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# IPMTC- AN EMERGING NURSING THEORY ON TRANSITIONING INDIVIDUALS WITH TRAUMATIC BRAIN INJURY FROM LONG-TERM CARE FACILITIES TO THE COMMUNITY UNDER MEDICAID WAIVER PROGRAMS

Sylvia Abbeyquaye

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IPMTC- AN EMERGING NURSING THEORY ON TRANSITIONING  
INDIVIDUALS WITH TRAUMATIC BRAIN INJURY FROM LONG-TERM CARE  
FACILITIES TO THE COMMUNITY UNDER MEDICAID WAIVER PROGRAMS

A Dissertation Presented

By

SYLVIA ABBEYQUAYE

Submitted to the Graduate School of the  
University of Massachusetts Amherst in Partial fulfilment  
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

September 2018

College of Nursing

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## DEDICATION

To my dear husband Tetteh Abbeyquaye and my three wonderful sons; Banafo  
Abbeyquaye, Nai Ntaski Abbeyquaye and Parbi Abbeyquaye

## **ACKNOWLEDGEMENTS**

It seems surreal that my doctoral study has come to an end. This journey has been eventful and fulfilling, and it would not have been possible without the help, counsel, and prayers of so many near and far. Words cannot adequately express my profound gratitude to everyone who helped me, and though there is not enough space to list all of the remarkable individuals who offered me their support, there are a few I must mention here.

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## **ABSTRACT**

**IPMTC- AN EMERGING NURSING THEORY ON TRANSITIONING  
INDIVIDUALS WITH TRAUMATIC BRAIN INJURY FROM LONG-TERM CARE  
FACILITIES TO THE COMMUNITY UNDER MEDICAID WAIVER PROGRAMS**

**SEPTEMBER 2018**

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This study aims to explore the process of transitioning individuals with traumatic brain injury (TBI) from long-term care settings to the community and develop a theory of transition. Also, it explores the definition of successful transitioning and the perceived role of the nurse in the transitioning process. A constructivist grounded theory method guided by symbolic interactionism was used in this study. The research sample was recruited throughout the Commonwealth of Massachusetts. The sample included individuals with TBI, family caregivers, professional caregivers, and community service providers involved with the Acquired Brain Injury and the Money Follows the Person waiver programs in Massachusetts. Data for this study was obtained through interviews, participant observations, photography, and document reviews. Thematic analysis was used to explore and define successful transitioning and the perceived role of the nurse in



transitioning through synthesis and abstraction of the data collected. Analysis using grounded theory methods such as constant comparison, theoretical sampling, coding, memo writing, journaling, and theoretical saturation was employed as theory emerged. The “It’s all about the person model of transitioning to the community” (IPMTC) was the resulting theory developed from this study. As a theoretical model, IPMTC asserts that transitioning from a long-term care facility to community will be successful if: the transitioning process is person-centered; a supportive environment is maintained; the health of the individual transitioning is stable; there are effective transition management processes in place, and there are facilitating individual, process, systems, and organizational factors. The IPMTC asserts that transition outcomes will be suboptimal if there are barriers to the process. As an emerging nursing theory, IPMTC defines the four essential components of nursing (person, health, environment, and the role of the nurse). The IPMTC is ground-breaking as it is the first to describe the process of transitioning individuals with TBI from long-term care setting to the community under a Medicaid waiver program. The first to place transition management processes within the context of a broader transitioning process and shows that the transitioning process is a nursing process. The IPMTC indicate that checking in, planning, relationship-building, and social engagement are key transition management processes.

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# **CHAPTER 1**

## **RESEARCH OBJECTIVES**

### **Introduction**

Individuals with Traumatic Brain Injury (TBI) and resulting disabilities are being discharged from long-term healthcare facilities to home throughout the United States in increasing numbers. Their transitioning to less restrictive settings in the community is supported by Medicaid waiver programs, implemented across the United States (Reinhard, 2010, 2012) due to the associated healthcare cost savings (Harrington, Ng, & Kitchener, 2011). Since 2008, with the support of Money Follows the Person (MFP) grants, 45 U.S. states have transitioned over 51,823 Medicaid beneficiaries, including individuals with TBI, from nursing homes to the community (Morris et al., 2015). Yet, individuals with TBI who transition to their homes have been found to experience significant challenges (Abrahamson, Jensen, Springett, & Sakel, 2016; Piccenna, Lannin, Gruen, Pattuwage, & Bragge, 2016; Turner et al., 2007), including decline in functional ability, poor community integration, and psychosocial reintegration (Doig, Fleming, & Tooth, 2001; Sander, Pappadis, Clark, & Struchen, 2011; Sandhaug, Andelic, Langhammer, & Mygland, 2015; Williams, Rapport, Millis, & Hanks, 2014). Individuals with TBI living in long-term healthcare settings, though younger than other residents, are at a greater risk for failed community placement and poor community reintegration, as they are likely to have severe TBI (Eum et al., 2015). Owing to their significant physical deficits, as well as cognitive and executive functioning impairments, they also tend to experience neurobehavioral disturbances (Lengenfelder, Arjunan, Chiaravalloti, Smith, &

DeLuca, 2015). While such transitions are occurring, the strategies used in managing them remain unknown. To help mitigate these risks and improve transition outcomes, it is critical to understand how individuals with TBI, and their family caregivers as well as professionals and community service providers, currently manage their transition from long-term healthcare facilities to home after many months of institutionalization.

A few studies, most conducted in Australia, have concentrated on transitioning individuals with TBI from hospital and acute inpatient rehabilitation facilities to home, but not from a long-term healthcare facility to home. When such studies have been conducted, they have focused predominantly on the transition experiences of the individual with TBI and their family caregivers and reported outcomes of emotional distress, caregiver strain, and poor community integration (Abrahamson, Jensen, Springett, & Sakel, 2016; Cornwell et al., 2009; Nalder, Fleming, Cornwell, & Foster, 2012; Nalder et al., 2016; Nalder, Fleming, Cornwell, Shields, & Foster, 2013; Nalder, Fleming, Foster, et al., 2012; Turner, Fleming, Cornwell, Haines, & Ownsworth, 2009; Turner et al., 2007; Turner, Fleming, Ownsworth, & Cornwell, 2011; Turner et al., 2010; Turner, Fleming, Ownsworth, & Cornwell, 2011; Turner, Fleming, Ownsworth, & Cornwell, 2008). On the other hand, studies that have explored general transitions from long-term healthcare facilities to communities, usually with Medicaid waiver program support, have primarily focused on older adults with other chronic illnesses and not TBI (Fields, Anderson, & Dabelko-Schoeny, 2011; Robison, Porter, Shugrue, Kleppinger, & Lambert, 2015; Robison, Shugrue, Porter, Fortinsky, & Curry, 2012; Winkler et al., 2011). These studies looked at the various elements involved in transitioning aspects of care delivery across settings. i.e., care coordination, medication reconciliation, follow-up

services, and case management (Chhabra et al., 2012; Toles, Colón-Emeric, Naylor, Barroso, & Anderson, 2016). They report a fragmented process due to a lack of knowledge about the process (Toles, Colón-Emeric, Naylor, Barroso, & Anderson, 2016) and poor communication and coordination during discharge planning processes (Golden, Martin, da Silva, & Roos, 2011; Meador et al., 2011; Toles et al., 2016). These directly impact transition outcomes such as 30-day readmissions, the number of Emergency Department (ED) visits post-discharge, as well as patient satisfaction (Camicia et al., 2014; Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). To date, no known studies in the United States have explored the process of transitioning adults with TBI from long-term healthcare facilities to the community. This research study addressed these research gaps by carefully examining the interactions among and between individuals with TBI, their families, professional caregivers, and community service providers during the process of transitioning to the community from long-term healthcare facilities.

### **Research Questions**

This research study thoroughly explored the actions and interactions among and between individuals with TBI, their families, professional caregivers, and community service providers through social interactions. Social interaction is the way persons, groups, or social systems act toward and mutually influence one another (Bardis, 1979). The guiding question for this qualitative research study was “What is the social processes involved in transitioning adults 18 years and older with TBI from long-term healthcare facilities to the community?”

The study also addressed the following specific questions: a) what processes were used by individuals with TBI and their families to manage their transitions from long-term healthcare facilities to community? b) What processes were used by professional caregivers to manage transitions involving the individual with TBI and their families from long-term healthcare facilities to community? c) What processes were used by community service providers to manage transitions of individuals with TBI and their families from long-term healthcare facilities to the community?

### **Study Purpose**

The purpose of this study was to develop a theoretical model of transitioning adults with TBI from long-term healthcare facilities to the community. The model developed elucidates the social processes integral to the transition experience of individuals with TBI, their families, professional caregivers, and community service providers during transitioning to the community.

### **Specific Aims**

The specific aims of this research study were as follows:

- I. To explore the meaning of a successful transition from long-term healthcare facility to community among individuals with TBI, their family members, professional caregivers and home and community-based service providers;
- II. To describe the social processes of transitioning from long-term healthcare facilities to community from the perspective of the individuals with TBI, their

family members, professional caregivers, and home and community-based service providers;

- III. To explore the role of nursing in the transition process from the perspective of the individual with TBI, their family members, professional caregivers, and home and community-based service providers;
- IV. To develop a theory of the social processes of transition for individuals with TBI grounded in the meanings they, their family members, professional care providers, and home and community-based service providers attribute to the process of transitioning from a long-term healthcare facility to the community.

### **Definition of Key Terms**

#### **Social Processes**

The product of social interactions which addresses, among others, issues of cooperation, competition, and conflict. Social interaction is the way in which personalities, groups, or social systems act toward and mutually influence one another (Bardis, 1979).

#### **Transitions**

Transitions will be defined here as the process of moving individuals with TBI from a long-term healthcare facility to a non-institutional residence (ABI/MFP Medicaid waiver approved residential group homes).

### **Individual with TBI**

Adult 18 years or older who sustained a TBI as an adult and lived in a long-term healthcare facility for at least 90 days before transitioning to the community.

### **Traumatic Brain Injury**

Traumatic brain injury is defined as an alteration in brain function or other evidence of brain pathology caused by an outside force, usually a violent blow to the head (Menon, Schwab, Wright, & Maas, 2010).

### **Family Caregiver**

Adult 18 years or older, identified as a close relative or friend of the individual with TBI and who was the primary caregiver and had been involved in the process of transitioning the individual with TBI from long-term healthcare facility to the community.

### **Professional Caregivers**

Any healthcare worker (case manager, social worker, nurse practitioner, registered nurse) who took part in transitioning individuals with TBI from long-term healthcare facilities to community.

### **Home and Community Based Services**

Organizations (state and private funded) that provided community-based support services (day program services, visiting nurse and home care service agencies, group

home providers, and brain injury support groups) to individuals with TBI and their families in the community.

### **Home and Community Based Service Providers**

The staff of organizations (public and private funded) that provided community support services (day program services, visiting nurse and home care service agencies, group home providers, and brain injury support groups) to individuals with TBI and their families in the community.

### **Long-Term Care Facility**

A long-term care facility is defined in this study as an institution that provided long-term care services to individuals with TBI. Such institutions included nursing homes, skilled nursing facilities and chronic specialized neuro-rehabilitation units and hospitals where the individual with TBI resided for more than 90 days.

### **Community**

A non-institutional residence including group homes, individual residences, congregate housing, adult foster care homes and shared living homes. However, to ensure homogeneity, researcher adopted a narrow definition of community to include only group home settings.



## **Methodological Overview**

Transitioning is a complex process that involves many entities and stakeholders whose varied philosophical and cultural perspectives significantly influence the transitioning process. This study examined the transition experiences of individuals with TBI, their family caregivers, and other stakeholders through social interactions with the purpose of exploring how these individuals, their families, professional caregivers and community service providers manage the return of the individual with TBI to the community from long-term healthcare settings. Since little was known about the transitioning process, a qualitative approach was adopted to answer the research question: “what are the social processes involved in the transitioning of young and middle-aged adults (18-65 years) with TBI from long-term healthcare facilities to community?” More specifically, the study looked to develop a theoretical model about transitioning from a long-term healthcare facility, hence a constructivist grounded theory method as postulated by Charmaz (Charmaz, 2006, 2014) was used throughout the study. Sample was recruited across the entire state of Massachusetts through the Department of Developmental Services (DDS), a state agency that plays a key role in managing the transitioning and placement of individuals with Acquired Brain Injury (ABI), including TBI, from long-term healthcare facilities to residential group homes in the community under the Acquired Brain Injury (ABI) and Money Follows the Person (MFP) Medicaid waiver programs in Massachusetts. The research sample in this study included: a) Individuals age 18 years or older with TBI who are enrolled in the ABI/MFP waiver programs across the state of Massachusetts; b) Family caregivers of individuals age 18 years or older with TBI who are enrolled in the ABI/MFP waiver programs across the

state of Massachusetts; c) professional caregivers, including DDS service coordinators and social workers working in long-term healthcare facilities across the state; d) community service providers, which included program directors and staff of approved waiver residential group homes, including Seven Hills, Life Stream and Service Net across the Commonwealth of Massachusetts. Other community-based providers also took part in the study and they included staff from the Massachusetts Association of the Blind (MAB), who provide rehabilitation services to waiver participants living in residential group homes across the Central-Western region of the Commonwealth, and Transition Coordinators from New England Independent Living Program, Inc. (NILP) in Lawrence MA, who provide outreach services and help coordinate the transition process. Data were collected using in-depth interview, observation, and document review. Theoretical sampling consistent with grounded theory methods was employed throughout the study.

This research study was guided by symbolic interactionism as it explored the meaning individuals with TBI, their caregivers, professional caregivers, and community service providers attribute to their transitioning experience through social interactions. Symbolic interactionism is a social theory that postulates that meaning is found through human interaction and communication and is facilitated by words, gestures, and other symbols that have acquired conventionalized meanings (Blumer, 1969). Individuals with TBI recruited for the study had some cognitive and physical disabilities and were mostly non-verbal or had significant speech impairments. Therefore, to make meaning of their transition experiences, this researcher interacted closely with the participants during the study. This researcher used both verbal and nonverbal communication gestures to make

meaning of their transition experience, as was congruent with the tenets of symbolic interactionism. Furthermore, the key concept “transitioning to the community,” as used in this study, was a constructed meaning of a continual process over time, influenced by myriad factors. Transitioning to the community is an emotional and a physical process for the individual with TBI. The dynamic nature of the transitioning process makes this concept congruent with the assumptions of constructivism where “the truth” is flexible and relative (Charmaz, 2006, 2014). Thus, using an iterative process of induction and deduction consistent with constructive grounded theory methods, this study analyzed the perceptions, actions, and interactions of study participants and constructed a theoretical model grounded in the data.

Data analysis included four parts: the exploration of the definition of a successful transition, the exploration of factors influencing the transition process, proposal of a preliminary model on transitioning from long-term care facility to community and exploration of the perceived role of the nurse in the transition process. Thematic analysis was used to explore the definition of a successful transition, the factors influencing the transition process, and the perceived role of the nurse in the transition process. A theory was constructed using initial, focused, and theoretical coding methods involving an iterative process of constant comparison, memo writing, theoretical sensitivity and reflexivity, theoretical sampling, and theoretical saturation, congruent with a constructivist grounded theory method (Charmaz, 2006). Due to the large volume of data collected, a qualitative software for data management and analysis (NVivo 11) was also used to help with the organization and analysis of data.

### **Significance**

This study is significant as it has developed a new and substantive theory of transitioning individuals with TBI from long-term care settings to the community that is grounded in their experiences. This contribution is substantial in advancing nursing science and providing direction for future research and provides implications for nursing practice.

### **Knowledge Development**

This study explored the process of transitioning from a long-term care facility from the perspective of the individual with TBI, their family caregivers, professional caregivers (service coordinators, social workers, nurses), and community service providers. Thus, the findings of this study are extensive, and will largely contribute to furthering the existing knowledge in long-term care transitions. Also, this study proposes a new theoretical model explaining how individuals with TBI and their families, professional caregivers, and community service providers manage the transition process from a long-term care facility to the community. The developed model of transitioning to the community (IPMTC) will give insight on what transitioning to the community is about, how it is initiated, planned, and successfully implemented. Through this work of research, readers will be able to understand the complex phenomenon of transitioning to the community from the concepts, properties, dimensions, and categories developed in this study.

### **Research Directions**

The development of a theoretical model of transitioning to the community has laid the foundation for future research, as it asserts new inquiries and highlights new relationships and assumptions ideal for further qualitative and quantitative studies in transitions and discharge processes. Furthermore, the development of this model will lead to research focused on intervention strategies to support discharges of TBI patients and their families to the community and their lives after discharge. Since this study was focused only on individuals with TBI, there is also the opportunity to test the applicability of this proposed theory in other populations and different settings. Such studies will further advance the development of this preliminary model to a formal theory on long-term care transitions.

### **Practical Implications**

The It's All About the Person Model of Transitioning to the Community (IPMTC) has many practical implications, as it could serve as a framework to guide health professionals, community service providers, families, and patients in defining objectives and developing strategies for successful discharge from a long-term care facility to home. Also, this study has the potential to contribute to health professionals' efforts aimed at improving transition outcomes, as this study also unveils some practical strategies for successfully living in the community well after discharge.

## **Summary**

The institutionalization of adults with disabilities in long-term healthcare facilities is a matter of human dignity. It is therefore critical that transitioning young adults with TBI from long-term healthcare facilities to home be carried out meticulously and flawlessly to ensure successful outcomes such as community re-integration, improved quality of life and wellbeing, and dignity. Research conducted to date has not examined interactions between and among individuals with TBI, their families, and other stakeholders, such as professional caregivers and community-based service providers, as they transition from long-term healthcare facilities back to the community. This study aimed to explore the transition experience of young and middle-aged individuals with TBI, their family caregivers, professional caregivers, and community service providers through their social interactions, and to develop a theory. The research question “what are the social processes involved in transitioning adults 18 years and older with TBI from long-term-care healthcare facilities to the community?” was answered using an iterative process of induction and deduction consistent with grounded theory methods (Charmaz, 2006).

The significance of this research will be to further the understanding of how the transition process from a long-term healthcare facility to the community is managed through the perspective of individuals with TBI, their family caregivers, professional caregivers, and community service providers. A theoretical model of transitioning to community involving the individuals with TBI, their families, professional caregivers, and community service providers over a trajectory of phases, and grounded in their experiences, has evolved. This study has provided new knowledge and a framework to guide transition practices and subsequent research. Study findings promise to positively

impact how long-term care transitions to the community are managed, and subsequently, improve transition outcomes for the individuals with TBI and their families.

### **Delimitation/Scope of Study**

Transitioning from long-term healthcare facilities to home is a current national initiative, one which is complicated, and which involves many stakeholders (both private and public) with different interests and ideologies. This study could have delved into all aspects of this important issue, but time and financial constraints made this unfeasible. As such, this study focused only on individuals with TBI who transition under Massachusetts ABI and MFP Medicaid waivers to a group home setting in the community. Specifically, this research targeted young and middle-aged adults with TBI between the ages of 18-65 years who met the eligibility criteria for both waivers and matched the age group most enrolled in the program. Massachusetts offers a wide range of home and community-based service providers for this population. For this study, a subsection of these agencies was examined: residential service providers (group homes); community-based rehabilitation services through MAB; and transition service coordinators from NILP. The study included only professional care providers, such as the nurses, service coordinators, occupational therapists, and social workers who are directly involved in the transition process. Family caregivers of individuals with TBI enrolled in either the ABI or MFP waiver program also were included. The study was across the entire Commonwealth of Massachusetts to ensure appropriate sample size. Setting parameters for inclusion of study participants and research settings ensured that the study was manageable and focused, given the time and financial constraints.

## **CHAPTER 2**

### **REVIEW OF THE LITERATURE**

#### **Introduction**

The last several decades have been marked by a movement to transition individuals with disabilities away from institutional living and toward community dwelling. In the U.S., this increasingly prevalent practice initially targeted individuals with mental illness and children with disabilities and resulted in the closure of mental institutions and care facilities in the 1970's (Davis, Fox-Grange, & Gehshan, 2000). This strategy was recently expanded to include older individuals with disabilities, who thus had to return to the community after being discharged from long-term care institutions. The United States Supreme Court (*Olmstead v L.C.*, 1999) decided that individuals with disabilities, including TBI if appropriate, should receive assistance at home and community-based services (HCBS) instead of being isolated in institutions (Teitelbaum, Burke, & Rosenbaum, 2004). Since this landmark case, such transitions have become more frequent. To facilitate this initiative, in 2005 the Deficit Reduction Act (Pub.L. 109–171, S. 1932, Section 6071) was passed, prompting the creation of the “Money Follows the Person Demonstration Program (MFP)” (p. 102). Under this act, states were offered grants to “rebalance” their long-term care support services and make targeted Medicaid reforms to strengthen their community-based infrastructure. This initiative aimed to ensure that individuals with disabilities have a choice of where they live and receive services. The Patient Protection Affordable Care Act (ACA) in 2010 expanded



the MFP demonstration initiatives (Bohl, Schurrer, Lim, & Irvin, 2014). Since 2008, with the support of MFP grants, 45 U.S. states have transitioned 51,823 Medicaid beneficiaries from nursing homes to the community (Morris et al., 2015). Given the fact that such transitioning is occurring, very little is known about what these transitions entail, how they are managed, the outcomes of such transitions, the effect of these transitions on the individuals and families, the factors influencing the transitions, and the role of the healthcare professionals in the process.

This chapter presents the review of literature about transitioning individuals with TBI from a long-term health care setting to the community. Currently, no literature exists that directly addresses this issue. However, there is a plethora of work carried out, primarily in Australia, on the transitioning experience of individuals with TBI from acute care and inpatient rehabilitation settings to the community. This body of literature will be used by the proxy to help understand the current processes involved in transitioning individuals with TBI to the community. A second review specific to long-term care transitions to the community was also warranted as studies, though focused on long-term care transitions, were specific to other populations aside from individuals with TBI. The third review was on the care delivery aspects of transitions specific to nursing practice during long-term care transitions to home. The processes of review of the literature are reported below. Findings from the three reviews are summarized and presented in the following six sections: 1) transitioning from a healthcare setting to community, including psychological factors (feelings of shock, uncertainty, excitement, self-awareness, acceptance, hopefulness, and adjustment); 2) physical processes of transitioning (procedural and structural elements); 3) factors influencing transitions (supports, health

and functional ability, facility and market factors and environment); 4) barriers to transition; 5) transition outcomes; and 6) transition intervention programs.

### **The Process of Review of the Literature**

To obtain a review sample, a comprehensive search of the literature was conducted in November of 2016 and updated in January of 2018 using electronic keyword searches in five electronic databases as follows: Cumulative Index to Nursing and Allied Health Literature CINAHL, PsycINFO, Academic Search Premier, PsycARTICLES, and Social Sciences Abstracts. The keywords used in the search were: “traumatic brain injury,” “transition(s),” “brain injury,” “discharge,” “community,” and “home.” These terms were used singly and in combination as part of the search.

Inclusion criteria were as follows: a) scholarly peer-reviewed articles from 2007-2016; b) articles that focused on the transition of individuals with traumatic brain injury and/or acquired brain injury from all healthcare settings to home/community; and c) articles that focused on the transition experience of caregivers for individuals with traumatic brain injury(TBI) and/or acquired brain injury (ABI) from all healthcare settings to home/community. Articles were limited only to those published in English. Exclusion criteria were as follows: a) non-peer reviewed articles outside of the year range 2007-2016; b) articles with a focus other than TBI or ABI transitions from healthcare settings to home/community; c) articles focused on the transition of children and/or adolescents with TBI and/or ABI; and d) articles published in a language other than English.

Initially, a broad search of scholarly peer-reviewed articles published from 2007-2016 with term “transitions” yielded 375,738 articles with 0 article selected. A search strategy using a combination of keywords with the term “transitions” yielded a total of 627 articles. These titles and abstracts were reviewed, and 597 articles were excluded either because they did not meet the exclusion criteria or because they were duplicate articles. Thirty (30) full-text articles were read and evaluated and based on the inclusion criteria, 20 articles were initially selected. A review of article references yielded no additional literature appropriate to add to the selected articles. Hence, a final sample of twenty (20) articles was chosen for examination and synthesis of literature published about the subject.

Another keyword search of the following five electronic databases was done in December of 2016 and updated in 2018 as follows: 1) Cumulative Index to Nursing and Allied Health Literature or CINAHL; 2) PsycINFO; 3) Academic Search Premier; 4) PsycARTICLES; and 5) Social Sciences Abstracts. The search terms used were “transition(s);” “nursing home;” “long-term care facility;” “Medicaid waivers;” “skilled nursing facility;” “Money Follows the Person;” “traumatic brain injury;” “home;” and “community.” The terms were used singly or in combination with the keyword “transitions.” The search was limited to only those scholarly peer-reviewed articles published in English within the past five years (2011-2016).

Inclusion criteria were as follows: a) articles that focused on transition from the nursing home into the community or home; b) articles that focused on transitions of individuals with TBI or ABI from nursing home/skilled nursing facilities/long-term care facilities; and c) articles that focused on long-term care transitions under the Money

Follows the Person (MFP) and other Medicaid waiver programs. Exclusion criteria were as follows: a) non-scholarly peer-reviewed articles outside of set year range (2011-2016); b) all articles focused on transitioning to long-term care/nursing home/skilled nursing facility from acute care, home or other healthcare settings; c) articles focused on transitioning of children with brain injury from long-term care facilities; and d) dissertations, letters to editors, commentaries, and books.

An initial broad search of scholarly peer-reviewed articles from 2011-2016 with the term “nursing home” yielded 22,941 articles with (0) articles selected. A search strategy of combining keywords, yielded a total of 935 articles. Titles and abstracts were reviewed, and 912 articles were excluded, either because they did not meet the inclusion criteria or because they were duplicate articles. Twenty-three (23) full-text articles were read and evaluated, and based on the inclusion criteria, nineteen (19) articles were selected. Also, a review of references yielded four (4) more articles. Hence, a final sample of twenty-three (23) articles was used in the synthesis of the published literature.

A third keyword search of literature also was conducted to review articles about care transitions from long-term care and skilled nursing facilities. This search was conducted using the following five electronic databases: 1) Cumulative Index to Nursing and Allied Health Literature or CINAHL; 2) PsycINFO; 3) The Academic Search Premier; 4) PsycARTICLES; and 5) Social Sciences Abstracts. The search was conducted in December 2016 using the terms “care transitions,” “long-term care,” “nursing home” “traumatic brain injury” and “skilled nursing facility.” These terms were used singly or in combination with the term “care transitions.” This search, as in the previous search, was limited only to scholarly peer-reviewed articles published in English

from 2011 to 2016. Articles included were focused on care transition processes from long-term care to home/community as in the earlier search. Care transition articles focusing on acute care or settings other than long-term care and or skilled nursing facilities were excluded, as were dissertations, letters to editors, commentaries, and books.

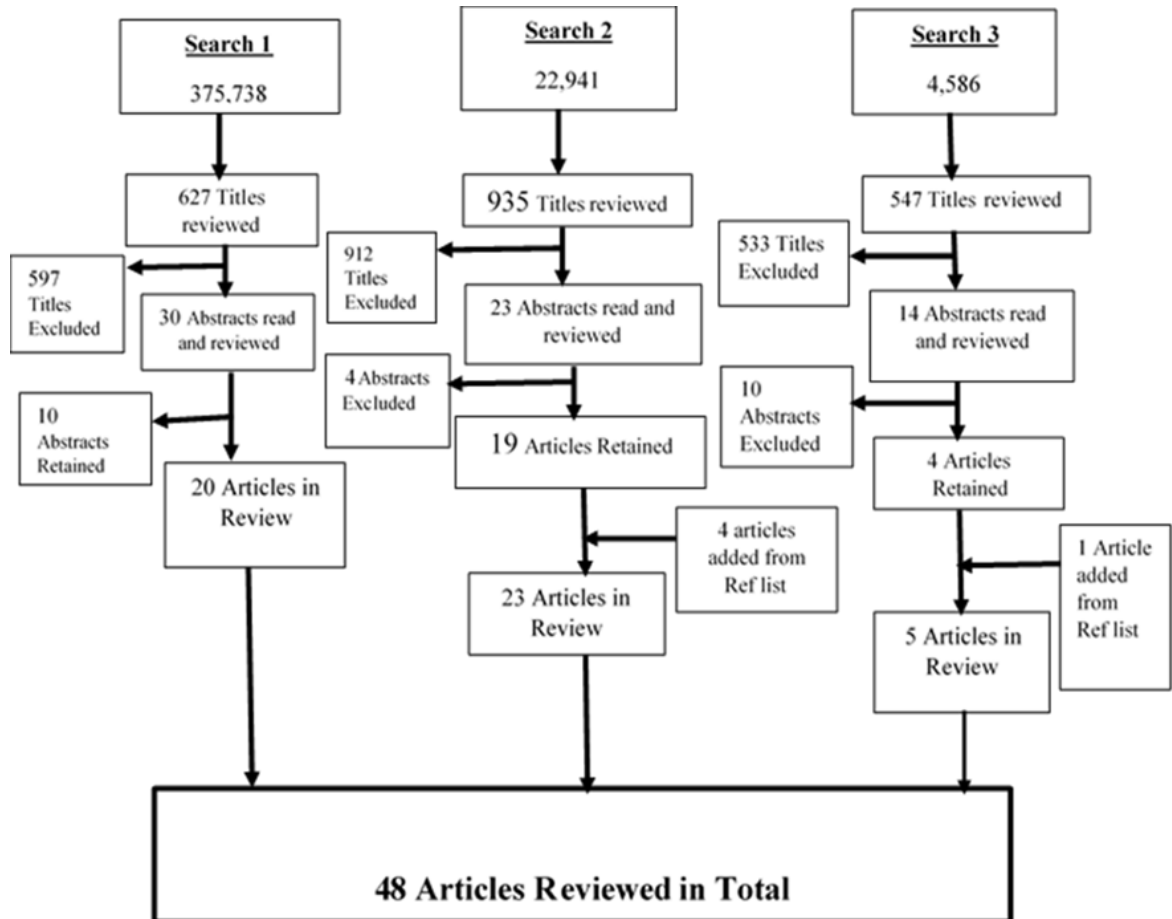


Figure 1: The process of review of literature.

A broad search of the term “care transitions” alone yielded 4,586 articles with zero (0) articles selected from the search. A following search strategy which combined keywords with the term “care transitions” yielded a total of 547 articles. Titles and abstracts were reviewed, and 533 articles were excluded, either because they did not meet

the inclusion criteria or because they were duplicate articles. Fourteen (14) full-text articles were read and evaluated. Four (4) articles were selected based on the inclusion criteria. A review of references yielded one (1) additional article. Hence a final sample of five (5) articles was used in the synthesis of the published literature.

The selected articles from all three searches were combined and uploaded as PDF documents into NVivo 10 @, a software package used for qualitative analysis. A total of 48 articles were included in the final literature synthesis. See Figure 1 above. A summary of search results is also shown in Table 1.

### **Results and Findings**

Table 1: Summary of Search results.

Search Results	Search 1 TBI Transition Literature	Search 2 Nursing Home Transition literature	Search 3 Care Transitions from Long-Term Healthcare to Home Literature	
Quantitative	6	10	1	17
Qualitative	12	*2	1	14
Mixed Methods	1	4	0	5
Review	2	6	2	10
Policy Papers/Case reports	0	1	1	2
<b>Total</b>	<b>20</b>	<b>*24</b>	<b>5</b>	<b>48</b>

\*Includes one paper that meets the inclusion criteria for both the TBI transition and the nursing home transition literature search.

### **Transitioning to Community from a Healthcare Setting**

Transitioning to the community from a healthcare setting is the process involved in ensuring a smooth return to the community after hospitalization, and rehabilitation.

Transitioning individuals with TBI is a complicated process, as it involves both

psychological and physical processes that occur simultaneously over time (Abrahamson, Jensen, Springett, & Sakel, 2016; Conneeley, 2012; Nalder, Fleming, Cornwell, & Foster, 2012; Nalder et al., 2016; Nalder, Fleming, Cornwell, Shields, & Foster, 2013; Piccenna, Lannin, Gruen, Pattuwage, & Bragge, 2016; Turner et al., 2007; Turner, Fleming, Ownsworth, & Cornwell, 2011; Turner et al., 2010; Turner, Fleming, Ownsworth, & Cornwell, 2008).

### **The Psychological Process of Transitioning**

The psychological process of transitioning pertains to the mental and emotional processes that occur as individuals with TBI return to the community and into the care of their families after hospitalization and rehabilitation. The emotions and sentiments expressed by both the affected individuals and their close family members are often mixed and include the feelings of shock, uncertainty, excitement, self-awareness, acceptance, hopefulness, and adjustment (Abrahamson et al., 2016; Conneeley, 2012; Turner et al., 2007). In many instances, these responses are incited by poor procedural processes engaged in by health professionals during the transitioning of care delivery. An in-depth review of findings related to the psychological processes, as experienced by individuals with TBI and their families during their return to the community is presented below.

#### **Feeling of Shock**

The sense of shock expressed by both individuals with TBI and their caregivers was evident in several studies and occurred very early in the transition process; immediately following injury, and again upon discharge to community (Abrahamson et

al., 2016; Nalder, Fleming, Cornwell, & Foster, 2012; Turner et al., 2007). The shock in response to the initial injury can be significant and often is experienced by caregivers, who also feel a heightened sense of anxiety at the time of the injury (Nalder, Fleming, Cornwell, & Foster, 2012). Caregivers continue to live with this sentiment of shock well after the person for whom they are responsible is discharged back to the community (Abrahamson et al., 2016). In contrast to caregivers whose sense of shock was associated with an increased sense of anxiety, the shock individuals with TBI experienced was associated with a heightened sense of awareness of their injury severity, and its impact on their functional ability to return to their life pre-injury (Turner et al., 2007). This sentiment was often associated with a lack of preparation for what to expect after returning to the community (Abrahamson et al., 2016). Individuals with TBI have high expectations about returning to their “normal” (pre-injury) lives in the community during their stay in the hospital. Thus, when they are faced with a new reality of long-term or permanent disability, the shock can lead to depression, anxiety, stress, anger, and social isolation (Turner et al., 2007; Turner et al., 2011).

“P10 – Yeah, when you come home it is a bit of a shock because all of a sudden you’re at home and like I say, I found it hard because I couldn’t do all the things that I used to do, and that’s what upset me. I wasn’t prepared for how much shock I got.” (Turner et al., 2007, p.1124)

### **Uncertainty**

Uncertainty will be defined as a state of doubt about the future. It is another emotional sentiment experienced by the individual with TBI and their caregivers during the process of transitioning to community, as they wonder what their fate and/or future would be



(Conneeley, 2012; Engström & Söderberg, 2011; Nalder, Fleming, Cornwell, & Foster, 2012; Turner et al., 2007; Turner et al., 2011).

“The trouble with this problem is that no-one can say to you, in a year’s time he’ll be X or Y or Z. The psychologist, with all their years of experience, they might think of something apart from, “Oh it’s early days yet, and everyone’s different.” I know it’s true, it takes time. I know it sounds silly but all we really want to know is, he’ll be 99% or he’ll be, if it doesn’t come back then we’ll have to learn to live with it, it would be nice to have some idea, which is one of the things they can’t supply you with.”(Conneeley, 2012, p.78 )

This sentiment of uncertainty was shared more often by caregivers of individuals with TBI (Conneeley, 2012; Engström & Söderberg, 2011; Nalder, Fleming, Cornwell, & Foster, 2012; Turner et al., 2007) and like the feeling of shock, it was felt very early in the process of transitioning when the life of the individual with TBI was hanging on a balance (Engström & Söderberg, 2011; Turner et al., 2007). This feeling of uncertainty about their life direction and future often caused higher levels of emotional distress such as anger, grief, sadness, fear and frustration among the caregivers (Nalder, Fleming, Cornwell, & Foster, 2012; Turner et al., 2007). Even though this sentiment of uncertainty was shared by individuals with TBI, it was reported in only one study and was expressed much later in the process, after discharge to the community (Turner et al., 2011). It should be cautioned that, in the study referenced, the focus was on individuals with Acquired Brain Injury (ABI). Even though 16/20 (80%) of the study participants had TBI, and only 4/20 (20%) had a stroke or an aneurysm, it is difficult to ascertain whether this sentiment of uncertainty was exclusive to the transition experiences of individuals with TBI or to anyone who has experienced an Acquired Brain Injury. It would be interesting to discover whether this sentiment of uncertainty is in any way influenced by the severity and type of brain injury experienced. Future studies in this area are thus

recommended.

### **Excitement**

As an individual with TBI recovers and gets ready for discharge back to the community, there is a shared feeling of excitement among both the individuals with TBI and their family caregivers. Their discharge to community marks a key milestone in their recovery and gives them a sense of achievement as well as hope for the future (Turner et al., 2011a). Individuals with TBI look forward to going home before they are discharged, and often have high expectations of what life at home will be like; hence, their excitement and happiness at the prospect of discharge (Turner et al., 2007).

“I: How did you feel when you first found out that you would be going home? P: Excited! (P8, pre)” (Turner et al., 2011, p.72)

This sentiment of happiness and excitement became stronger during the initial period of transition, when the individual with TBI returned to the community (Turner et al., 2007; Winkler, Farnworth, Sloan, & Brown, 2011) and gained more freedom to do as they wished at any particular time (Turner et al., 2011). Unfortunately, the sentiments of happiness and elation rapidly diminished for both the individual with TBI and their caregivers as they became more and more aware of the limitations they faced from the injury, as well as environmental and societal barriers (Turner et al., 2011). Their resulting disappointment often lead to feelings of depression, anxiety, and stress (Abrahamson et al., 2016; Nalder, Fleming, Cornwell, & Foster, 2012; Nalder et al., 2016; Nalder et al., 2013; Turner et al., 2010).

### **Self-awareness.**

Self-awareness is integral to the psychological process of transitioning individuals with TBI to the community (Turner et al., 2007; Turner et al., 2011). Individuals with TBI often experience greater impairment of self-awareness (Nalder, Fleming, Foster, et al., 2012), which impacts their ability to identify realistic life goals (Turner et al., 2008).

“C: I thought it would be better than it has been. I did not really expect the depression and the, you know, the agitation that has happened, I just thought, oh, we would be okay, we are going to be normal, and he will be okay, he would be able to go to gym, be able to do all his housework and you know... He just, you know, he just will not get off that chair half the time (C2, 1).” (Turner et al., 2011, p. 81)

In a study conducted to identify factors associated with the perceived success of the transition from hospital to home after a traumatic brain injury, a significant association between increased injury severity and higher ratings of transition success among individuals with TBI was reported (Nalder, Fleming, Foster, et al., 2012). This finding contradicted existing transition outcome studies. Nalder et al., (2012) explained this anomaly with their suggestion that the severity of injury may have caused greater impairment of self-awareness among study participants, leading to their underestimation of transition difficulties and hence, their higher self-rating of their transition success (Nalder, Fleming, Foster, et al., 2012). Even though this reasoning is logical, further studies must establish the validity of this hypothesis. The study was limited only to individuals with severe TBI, and as such, the findings may not be generalizable to the entire TBI population.

Similarly, a quantitative study which profiled and compared perceived changes in global functioning and psychosocial functioning at three-time points during transition

from hospital to home, reported significant main effect of perspectives between the participants with brain injury and their family caregivers in all domains of global and psychosocial functioning (Turner, Fleming, Cornwell, Haines, & Ownsworth, 2009). It was interesting to note that participants with brain injury often reported fewer problems than the family caregivers at all-time points and rated their functioning higher than caregiver's ratings on their functional abilities. The study assumed that caregivers provided more accurate and objective ratings and suggested that the difference in perspective could be because of ongoing deficits in self-awareness of the individual with brain injury (Turner et al., 2009). The sample size used in this study was small, which may have limited the power of the study. Also, the study sample was mixed with 80.8% having TBI and 19.2% having other acquired brain injuries including stroke, aneurysm, and encephalopathy. Although individuals with TBI were the most studied, findings are not exclusive only to this population.

Even though self-awareness among individuals with TBI is said to be poor, there is an indication that during the transition to home, their self-awareness improves. For many, the extent and impact of their injury are not realized until they return to the community (Conneeley, 2012; Turner et al., 2007). This improvement is seen within specific domains of functioning that are more related to task performance such as living skills and work activities (Turner et al., 2009). Receiving either internal (thoughts and feelings) or external (observation) feedback helps in improving their self-awareness (Turner et al., 2009). As individuals with TBI pursue larger goals of participation in the community, the impact of their injury-related deficits became clearer further improving their self-awareness (Turner et al., 2011). As they develop greater self-awareness and

recognize their post-injury changes, their sense of loss intensifies which may lead to anger and emotional distress (Turner et al., 2011). It is therefore not surprising that level of self-awareness has been identified as one of the many personal factors that influence a successful transition from hospital to home among individuals with acquired brain injury (Turner et al., 2008). Undoubtedly, the transition from hospital to home is a critical time in which self-awareness of deficits emerges with its associated emotional reactions. It is, therefore, necessary to also place emphasis on the psychological processes of transitioning individuals with TBI to the community and develop proper interventions.

### **Acceptance.**

Individuals with TBI and their caregivers experience significant changes in their lives because of their injuries (Abrahamson et al., 2016; Conneeley, 2012; Engström & Söderberg, 2011; Nalder, Fleming, Cornwell, & Foster, 2012; Nalder et al., 2013; Nalder, Fleming, Foster, et al., 2012; Turner et al., 2007). These changes are life-altering, since they impact all areas of functioning (Abrahamson et al., 2016), including the return to work and driving (Nalder et al., 2013), as well as the performance of life roles (Engström & Söderberg, 2011) and establishing and maintaining relationships (Engström & Söderberg, 2011; Nalder, Fleming, Cornwell, & Foster, 2012; Nalder et al., 2013). To adjust to life in the community amidst these circumstances, individuals with TBI and their caregivers learned to be accepting of these changes in their lives (Nalder, Fleming, Cornwell, & Foster, 2012; Nalder et al., 2013). Acceptance was not easily attained by individuals with TBI as they transitioned to the community. For some participants, acceptance was a continual struggle, as they often slipped into an attitude of denial

(Turner et al., 2011). One participant in a study, for example, described his journey in the following way: “It’s like being in a dream, can someone wake me up (P12, 1),” (Turner et al., 2011 p.84). Other studies reflect similar emotional challenges facing the individual with TBI and his/her family caregivers.

“PARU106 P: ... I know where I want to go, I know what I’m capable of doing. But it’s, ah, at the end of the day it’s not up to me. It’s up to [Insurance company] and my doctor. So, I guess I’ve never been one to like things to be taken out of my hands, but I’ve just had to accept it. So, they’re the things that have changed. I’ve had to readjust to that type of way of handling things.” (Nalder et al., 2013, p.1298)

In a qualitative study to reflect on the transition experiences of individuals with TBI and their caregivers, some participants described achieving acceptance, whilst others were still learning to come to terms with their different life even though they acknowledged the need to change their perspective on life. Participants in this study particularly did acknowledge that acceptance was a process they had to work through (Nalder et al., 2013). Those that felt that their lives had returned to normal showed acceptance of their new self and used compensatory strategies to get by in their work and other daily activities (Nalder et al., 2013). This was evidence of the probable link between acceptance and the yearning for normality. Furthermore, study showed that the ability and time to reach acceptance varied from one individual to another. Achieving acceptance was often dependent on the individual’s appraisal of the event, as well as other factors such as supports and self-awareness (Nalder et al., 2013). Again, study noted that individuals who showed greater acceptance of their situation demonstrated self-awareness regarding their ability to return to work. Overall study was rigorous, and findings were well supported with participants’ interview data. Study recruited from only one hospital and excluded individuals transferred to other healthcare facilities, such as

long-term healthcare facilities. Therefore, caution should be taken in transferring findings to the entire TBI population, especially those transitioning from long-term healthcare facilities to community. This limitation does not take away from the richness and insights of the participants' transition experiences, which is valuable to the proposed study.

The findings from Nalder et al (2013), that indicated that supports were needed in achieving acceptance, was strengthened by another qualitative study (Turner et al., 2007). Study was more specific in the type of supports needed to achieve this sentiment of acceptance. Having close and supportive friendship networks helped individuals feel more relaxed and comfortable about engaging in social activities, which in turn facilitated a feeling of acceptance for the individuals with TBI. Note that study sample was mixed and included individuals with other acquired brain injuries. Even though individuals with TBI made up 50% of the sample, findings were not exclusive to the TBI population and study cannot be generalized. This study, like the previous one, was rigorous and study findings were supported with actual interview data. Using semi-structured interviews with open-ended questions allowed for a rich account of participant experiences, consistent with the phenomenological design adopted for the study. It is obvious from these studies that reaching acceptance is critical for achieving transition success and attaining normality for individuals with TBI who transition to community.

### **Feeling Hopeful.**

Like the feeling of acceptance, feeling hopeful was also one other sentiment that the individuals with TBI and their caregivers experience during the process of transitioning to the community. Despite the high level of emotional distress that

individuals with TBI and caregivers experience during their transition to the community, many of them were often hopeful about the future (Conneeley, 2012; Engström & Söderberg, 2011; Nalder, Fleming, Cornwell, & Foster, 2012; Turner et al., 2011). The sentiment of being hopeful was expressed mostly by the family caregivers, who wanted to see their loved ones move past the injury and regain normality (Nalder, Fleming, Cornwell, & Foster, 2012).

“S: Um, it’s all just milestones I guess. Ah, like even when he was in the hospital, I had a photo of him when he was driving trucks. It’s still on my phone actually. When he was in the mines. And that’s where I believe he’ll return to. So, we just, you know, you don’t . . . That’s what you’re focused on. That’s where he was, and that’s where he’ll go back there. And at night time before you go to bed, that’s the last thing you look at. You try not to focus on what, what is. It’s what will be. Where you want it to be (PARU106).” (Nalder, Fleming, Cornwell, & Foster, 2012, p. 114)

In a study understanding the transition experiences of family caregiver of individuals with TBI, authors noted that the degree of hope differed distinctively among the caregivers. Based on this premise, study differentiated the participants into three subgroups: 1) those that perceived that life had returned to normal; 2) those that felt hopeful that life will return to normal; and 3) those who felt uncertain about the future. Again, the study found that “wanting normality” was a big driver of hope. Caregivers who perceived that the life of the individual with TBI was getting back to normal felt more hopeful compared to other caregivers who felt uncertain of the future and were shifting their hopes and expectations. (Nalder, Fleming, Cornwell, & Foster, 2012). The study was qualitative, and although it gave a rich account of participant experience, the degree of hope as was frequently referenced in the study was not quantified and hence using this as a sole basis of differentiating caregivers into three subgroups could be perceived as farfetched. However, authors justified their assertions with actual interview



data.

Although wanting normality appears to drive the sentiment of hope, the need for information from staff during their transition experience was seen by some caregivers as a means of retaining a realistic hope (Engström & Söderberg, 2011). Even though hope was expressed mostly by the caregivers in most of the studies reviewed, individuals with TBI also shared this sentiment. A study by Winkler et al. (2011) showed that before transition from an aged care facility to the community, a participant expressed hope “to see her mates and hit the pub” (Winkler et al., 2011), indicating her yearn for normality. It is worth noting that this account was from only one participant and study sample included individuals with all-cause ABI. Since the sample was mixed, it is difficult to ascertain whether this is reflective entirely of a TBI transition experience. Feeling hopeful is an essential psychological process as it reduces the emotional distress experienced by the caregivers, enabling them to better cope with and adjust to life in the community as they looked forward to the future (Nalder, Fleming, Cornwell, & Foster, 2012).

### **Adjustment**

Considering the life-altering changes individuals with TBI and their caregivers go through during transitions to the community, it goes without saying that significant emotional adjustments are needed by both the individual with TBI and their family caregivers to ensure a smooth and successful process of transitioning to the community. Studies reviewed attest to the notion that adjustment evolves throughout the transition and it is critical to TBI recovery (Turner et al., 2011). Turner et al. find this period of

adjustment as a “transition phase” distinct on the rehabilitation continuum (Turner et al., 2007; Turner et al., 2011a; Turner et al., 2008); a period from pre-discharge to 3 months post-discharge. Other studies, however, indicate that the period of adjustment extends beyond three (3) months post-discharge (Engström & Söderberg, 2011; O'Neil-Pirozzi, Lorenz, Demore-Taber, & Samayoa, 2015).

Finding a balance between independence and the need for supports often required significant emotional adjustments for both individuals with TBI and their caregivers who transitioned to the community. Both often expressed frustrations, even for those who worked closely as a team (Abrahamson et al., 2016). The individual with TBI's frustration was with their reduced freedom, and they often felt over-protected, disempowered, and not listened to (Abrahamson et al., 2016). Caregivers, on the other hand, struggled with letting go, since they were often afraid of further harm to their loved ones and they were not trusting of their ability to make sound decisions (Abrahamson et al., 2016; Conneeley, 2012; Nalder, Fleming, Cornwell, & Foster, 2012). These frustrations experienced during transitioning often translated into conflicts between an individual with TBI and their caregivers and elicited counter-productive behavioral responses (Turner et al., 2011).

Adjusting back to the community is undoubtedly difficult for many individuals with TBI and their families (Abrahamson et al., 2016; Nalder, Fleming, Cornwell, Foster, & Haines, 2012; Turner et al., 2007; Turner et al., 2011) and requires significant support from family and friends as well as other support services (Nalder, Fleming, Foster, et al., 2012; Turner et al., 2007). Interestingly, the difficulty they experienced in adjusting to the community often took both the individual with TBI and caregivers by surprise

(Turner et al., 2011). This is partly because they often underestimated the changes in their abilities and roles and the impact on their daily lives once at home (Abrahamson et al., 2016). It could also be that poor discharge preparation given by professional staff during their transition to community fed into this experience of surprise. Professionals, just like the individual with TBI and their caregivers, often underestimated the profound changes in the abilities and roles of their clients once they returned home (Abrahamson et al., 2016) and hence, were unable to anticipate their needs accurately.

“The first time, the first day I came home, I was quite unprepared for the high degree of emotion. Everyone was concerned that I could walk up and down stairs on my own, climb in and out of the bath and all those sorts of things, but virtually no-one said anything about how I would react emotionally. (Ron)” (Conneeley, 2012, p.78)

“Nobody prepared me for home...Nobody said, ‘well, what you are going to do when you get there? ...I just needed a bit more guidance on how it was going to be (P1).’” (Abrahamson et al., 2016, p.6)

Shock, uncertainty, excitement, self-awareness, acceptance, hopefulness and adjustment were some common underlying sentiments and emotions identified from this review and were integral to the psychological process of transitioning. These sentiments significantly impacted the TBI transition experience and contributed to the emotional distress experienced by both the individual with TBI and their caregiver's post-injury.

### **The Physical Processes of Transitioning**

In the context of the present investigation, the term “physical process” pertains to the mechanics involved in physically moving an individual from a healthcare setting to their community and family care. The mechanics noted in the studies included in this review entailed both procedural and structural elements.

## **Procedural Elements**

Procedural elements are defined here as the established evidence-based processes and procedures that are currently practiced by health professionals when physically moving an individual from a healthcare setting to community. These include care transitions and case management processes.

### **Care Transitions**

During the process of returning an individual from a healthcare setting to the community, healthcare professionals engage in procedures to ensure a smooth transition of care delivery. This process is often referred to as care transition (Park, 2012; Toles et al., 2016; Toles, Young, & Ouslander, 2012). These procedures typically include discharge-planning processes of care coordination, goal setting, and medication reconciliation (Abrahamson et al., 2016; Chhabra et al., 2012; Toles et al., 2016). In some studies, the authors also noted follow-up through transitional care clinics (Park et al., 2013), as well as service coordination and case management (Golden, Martin, da Silva, & Roos, 2011) under this category. Only three studies focused on the care delivery aspects of the transitioning from long-term-care facilities, which were explored from the perspective of individuals with chronic illnesses other than TBI (Park, 2012; Park et al., 2013; Toles et al., 2016). In addition, research conducted in this field mostly pertained to specific interventions aimed at reducing hospitalizations and emergency department visits in the short-term (30 days), such as the use of transitional care clinics (Park et al., 2013), inter-professional collaboration (Reidt et al., 2016), and the use of a clinical pharmacist for effective medication reconciliation processes.

The few authors that have specifically examined processes of transitioning to the community as experienced by individuals with TBI and their families found them suboptimal (Abrahamson et al., 2016; Piccenna et al., 2016). The noted inadequacies were mainly attributed to poor communication among professional healthcare providers and family caregivers (Piccenna et al., 2016). Toles et al. (2016) recently conducted a qualitative study to describe and compare how transitional care services were delivered in three skilled nursing facilities (SNF), revealing significant flaws in the processes. According to the authors, discharge-planning services were inconsistent across and among the studied facilities. Care interactions and problem-solving strategies were inefficient and, at one SNF, care-planning meetings were not routinely conducted. The only SNF in this study that was outstanding in its transitional service delivery was staffed by nurses who fully understood the need for transitional services and conducted routine meetings to plan and implement transitional care services (Toles et al., 2016). However, even at the outstanding SNF, processes such as medication reconciliation were not implemented adequately.

### **Case Management**

Case management is another procedural element that health professionals engage in during the transition of an individual from a healthcare setting to the community (Abrahamson et al., 2016; Bardo, Applebaum, Kunkel, & Carpio, 2014; Cornwell et al., 2009; Golden et al., 2011; Meador et al., 2011; Turner et al., 2007; Turner, Fleming, Ownsworth, & Cornwell, 2011). This transition aspect may be prevalent because it was emphasized as an essential component of long-term care transitions under the Medicaid

waiver program (Bardo et al., 2014; Golden et al., 2011; Meador et al., 2011; Robison et al., 2015). Case management under the waivers is a comprehensive and a personalized long-term process that begins before an individual's discharge from a facility (Meador et al., 2011). These visits are one-on-one, and they help participants gain access to various community-based services, including home medical equipment, financial management, home modification to enhance accessibility, and dietary advice/support (Meador et al., 2011). This model of intensive case management, however, does not always ensure optimal outcomes. For example, upon reviewing the outcomes of Project Home, a New York Medicaid-funded program, Meador et al. (2011) reported that about 40% of the program participants could not successfully transition to the community despite intensive case management processes. This finding contrasts with positive results reported by Robison et al. (2015) following their assessment of Connecticut's Medicaid waiver program, which was based on a similar model. The authors noted positive outcomes in five of six quality of life domains and global life satisfaction. However, the re-institutionalization rate was 14%, and the incidence of falls also increased and remained above pre-transition levels. Although symptoms of depression declined significantly, about half of the study participants continued to report depressive moods. Emergency Department (ED) visits were consistently high as well (Robison et al., 2015). When interpreting these findings, however, it is important to note that this and other studies discussed here focused on older adults (aged 65 years and older) with chronic illnesses other than TBI.

For individuals living with TBI and their family members, case management processes are valuable during the transition to the community, because the assistance

offered helps them in organizing and accessing available supports and relevant information to ensure their success in the community (Turner et al., 2007; Turner et al., 2011). Moreover, having a designated case manager can help reduce strain on family members caring for individuals with TBI, as they may struggle with maintaining their pre-injury lifestyles and roles (Nalder, Fleming, Cornwell, & Foster, 2012). Most importantly, effective case management processes have a positive impact on the emotional wellbeing of the individual with TBI (Turner et al., 2007). Despite these positive outcomes, case management services are often limited and not easily accessible for the individuals with TBI after they return to the community, placing a significant strain on their families (Cornwell et al., 2009; Turner et al., 2007; Turner et al., 2011).

Overall, evidence yielded by this comprehensive review indicates that the procedural elements engaged in by health professionals during the process of transitioning individuals with TBI are poorly managed, especially when offered in long-term care settings. However, case management processes in long-term care under the Medicaid waiver programs are described as well coordinated, efficient, and effective, albeit with some shortfalls.

### **Structural Elements**

The transitioning process from a healthcare setting requires structural supports and services in place to ensure a successful reintegration to the community. The structural elements that were typically discussed in the pertinent literature included home- and community-based services, informal supports, social networks, housing, and staffing. These supports, and services are discussed in more detail below.

## **Home and Community-Based Services (HCBS)**

The HCBS is an umbrella term encompassing either private or publicly-funded formal supports in place in the community which are essential to a successful return and reintegration into community (Fields, Anderson, & Dabelko-Schoeny, 2011; Kane, 2012; Meador et al., 2011; Reinhard, 2010, 2012; Stoner & Gold, 2012), especially after long-term transitions. HCBS include rehabilitation services, day program services, group homes, transportation, home-delivered meal services, and personal care services (Kane, 2012). Individuals with TBI and their caregivers rely on these formal supports once the patients are discharged from the health facility (Cornwell et al., 2009; Nalder, Fleming, Foster, et al., 2012; Turner et al., 2011; Turner et al., 2008). Rehabilitation therapy services, for example, were identified by several authors as one of the most salient support needs among individuals with TBI and their caregivers, who typically found access to this service inadequate (Nalder, Fleming, Cornwell, Foster, Ownsworth, et al., 2012; Nalder et al., 2016; Turner et al., 2007; Turner et al., 2011; Turner et al., 2008). Difficulty accessing therapy among women with TBI has been associated with reduced participation in the community (Nalder et al., 2016). Also, limited participation in the community has been shown to negatively correlate with perceived transition success (Nalder, Fleming, Foster, et al., 2012). Several studies have shown that individuals with ABI living in rural and remote settings tend to have difficulty locating, and thus, accessing therapy services in their areas (Keightley et al., 2011; Turner et al., 2011). Different states, through Medicaid programs, provide a variety of formal supports, such as personal care services, day programs, group homes, transportation, and



home-delivered meal programs in the community to help bridge that gap (Kane, 2012; Reinhard, 2010, 2012; Stoner & Gold, 2012)

### **Informal Supports**

Due to the stringent eligibility criteria and financial barriers to accessing formal services such as HCBS, many individuals living with TBI rely heavily on informal supports from family and friends during their transition to the community and beyond (Fields et al., 2011; Leedahl et al., 2015; Meador et al., 2011; Noyes et al., 2014; Robison et al., 2012; Turner et al., 2011). These supports include physical, emotional, and financial support, assistance with domestic tasks and transportation, and providing respite to the primary caregivers (Turner et al., 2007). The support provided by the family is dependent on the nature of family relationships and the level of disability that the individual with brain injury experiences (Turner et al., 2007). Having a person that is willing to provide informal support and has a positive attitude towards discharge has been found to be a good predictor of successful transitioning from a nursing home to the community (Gassoumis et al., 2013). Individuals that provide informal support to those with TBI and other brain injuries often feel obliged to so as their loved ones' transition to community (Cornwell et al., 2009; Engström & Söderberg, 2011; Nalder, Fleming, Cornwell, & Foster, 2012; Turner et al., 2007; Turner et al., 2011). For example, if the individual with TBI is unable to drive, caregivers instinctively feel obliged to assist with transportation, which inevitably affects their lifestyle and routine (Nalder, Fleming, Cornwell, & Foster, 2012).

As individuals with TBI transition to the community, family caregivers often perceive a change in lifestyle and thus experience their own transitions. They are often faced with a new reality of helping their family member be less dependent (Engström & Söderberg, 2011) and attempt to return to “normal” life (Nalder, Fleming, Cornwell, & Foster, 2012). The enormity of their role cannot be understated, given that the responsibility for providing support usually rests on one or two key individuals (Turner et al., 2007). In several studies included in this review, participating caregivers reported that the supports needed to ensure a smooth transition to home life for the individuals with TBI were often lacking, causing the caregivers significant emotional distress (Abrahamson et al., 2016; Cornwell et al., 2009; Nalder, Fleming, Cornwell, & Foster, 2012; Turner et al., 2011).

### **Social Network**

Having a social network in place is structurally important for transitions, especially after long periods of hospitalization (Conneeley, 2012; Keightley et al., 2011; Lee et al., 2016; Meador et al., 2011; Nalder, Fleming, Cornwell, & Foster, 2012). Having a social network provides physical and emotional support, and enhances self-worth, and thus improves health outcomes for individuals transitioning to their community (Engström & Söderberg, 2011). Several authors cited the presence of social network and support as instrumental to successful coping during the transition to the community (Abrahamson et al., 2016; Conneeley, 2012). Unfortunately, many individuals with TBI lose their social ties and connections after injury and prolonged institutionalization, owing to the stigma related to having a TBI (Turner et al., 2007;

Winkler et al., 2011). Consequently, many experience social isolation, which compromises their health outcomes (Engström & Söderberg, 2011; Turner et al., 2007; Turner et al., 2011; Winkler et al., 2011). For example, one participant in the study conducted by Winkler et al. (2011) stated, “[Friends are] at university or working but it’s a huge problem how I can’t talk, remember or walk. I’m just an outcast now” (p. 162).

### **Housing**

Availability of affordable and accessible housing is another structural element integral to the transition process. Having an appropriate place to return to upon discharge from a care facility creates the right environment for the individual with brain injury to recover and thrive upon return to the community (Winkler et al., 2011). Several authors concur that inadequate housing is a major barrier to the transition process, especially after long-term institutionalization (Bardo et al., 2014; Fields et al., 2011; Leedahl et al., 2015; Reinhard, 2012; Robison et al., 2012). Many long-term residents give up their assets, including their homes, to qualify for Medicaid long-term care services. Consequently, they often have no homes to go to upon discharge from the care facility (Fields et al., 2011). Indeed, critics of transitions under Medicaid initiatives purport that successful return to the community from long-term healthcare facilities is very much dependent on housing availability (Fields et al., 2011). This issue is rarely raised by individuals with TBI and their caregivers during their transitioning to the community.

## **Staffing**

Adequate availability of qualified and competent staff is essential to ensuring a safe return of an individual with TBI to the community and is thus considered a structural element. Authors of many studies examining long-term care transition outcomes posited that the use of a multidisciplinary team is vital to the transitioning process (Bardo et al., 2014; Leedahl et al., 2015; Meador et al., 2011; Reidt et al., 2016; Robison et al., 2015; Stoner & Gold, 2012). The competence of staff in managing such transitions is reportedly suboptimal (Abrahamson et al., 2016; Toles et al., 2016). Caregivers of individuals with TBI tend to cite lack of compassion and empathy among professional staff, as issues important to them are often considered minor by staff and are thus not addressed satisfactorily (Abrahamson et al., 2016). For example, individuals with TBI wanted to focus on return to work or activities of similar value but felt that the staff gave priority to the more immediate goals, which did not support their long-term aspirations. The perceived differences between goals have been attributed to general staff incompetence and lack of knowledge about the transitioning process (Abrahamson et al., 2016; Toles et al., 2016)

## **Factors Influencing the Process of Transitioning to Community**

Transitioning to community is influenced by a myriad of factors identified in this review and they include: formal and informal supports (Cornwell et al., 2009; Turner, Fleming, Ownsworth, & Cornwell, 2011), injury severity (Nalder, Fleming, Cornwell, Foster, et al., 2012b), gender (Mudrazija, Thomeer, & Angel, 2015; Nalder et al., 2016), resident characteristics (Fries & James, 2012; Holup, Gassoumis, Wilber, & Hyer, 2016) ,

facility and market factors (Arling, Abrahamson, Cooke, Kane, & Lewis, 2011), availability and accessibility of resources (Cornwell et al., 2009; Turner et al., 2011), housing (Fields, Anderson, & Dabelko-Schoeny, 2011), organizational structures (Toles et al., 2016), substance abuse and mental health (Stoner & Gold, 2012), health and functional ability (Fries & James, 2012; Meador et al., 2011), societal attitudes (Abrahamson et al., 2016; Turner et al., 2007; Turner et al., 2011), funding and financial resources (Cornwell et al., 2009), and other environmental factors (Winkler et al., 2011) have also been identified. A few of the essential elements are discussed below.

### **Supports**

Supports, as discussed throughout this review appears to be the most profound factor influencing transitioning to the community. There is evidence that residents that have supports in place are more likely to transition to community although this may also be dependent on some other facility factors (Arling, Kane, Cooke, & Lewis, 2010). Supports here may be informal and/or formal supports, and they may include; social supports, financial supports, supports from healthcare and other professionals, environmental supports, psychological/emotional supports and home and community-based supports (Abrahamson et al., 2016; Lee, Hammel, & Wilson, 2016; Leedahl et al., 2015; Meador et al., 2011). In reviewing the literature, it was apparent that most of the unmet needs of individuals with TBI and their families during their transition to community is somehow associated with the lack of supports (Abrahamson et al., 2016; Cornwell et al., 2009; Keightley et al., 2011; Piccenna et al., 2016) which directly

impacts their emotional wellbeing (Nalder et al., 2013) and their transitioning to community.

### **Health and Functional Ability**

Health and functional ability is one factor that is also important but often underestimated in transitions, especially from long-term healthcare facilities to community under Medicaid waiver programs. This is evident by the minimal role nurses play in these Medicaid waiver programs and the adoption of the non-medical model (Bardo, Applebaum, Kunkel, & Carpio, 2014). There is a plethora of evidence suggesting that successful transition under the waiver programs is influenced mostly by health and functional status (Fries & James, 2012; Gassoumis, Fike, Rahman, Enguidanos, & Wilber, 2013; Meador et al., 2011a; Robison, Shugrue, Porter, Fortinsky, & Curry, 2012; Stoner & Gold, 2012). In characterizing participants of the Money Follows the Person Waiver in Arkansas, Michigan, and Illinois, it was found that participants who transitioned successfully were less dependent in their ADLs, less cognitively impaired and were younger compared to individuals who did not transition (Fries & James, 2012). This finding aligns with another study that showed that residents that remained in the long-term healthcare facility at 90 days were found to be older, more dependent in ADLs and IADLs, cognitively impaired and incontinent, and were less likely to transition into the community (Arling et al., 2011). Being severely cognitively impaired reduced the odds of discharge by 56% for residents who remained at a long-term care facility after 90 days, specifically between 91-365 days (Gassoumis et al., 2013). Again, findings from the qualitative phase of a mixed methods study suggested that medical complexity is one of three main barriers to transitioning from nursing home to community (Meador et al.,

2011). This assertion, however, did not hold up with the quantitative analysis of the same study, which indicated that medical complexity did not affect the expected discharge rate. The anomaly in finding could probably be due to the inadequate sample size  $n=60$ .

Despite the evidence that health and functional ability influences transitions, it is not a set criterion for eligibility under the Medicaid waiver programs. Some states, however, seem to recognize this and consider this as an integral factor in measuring their program success. Connecticut, for example, includes a health and well-being domain in measuring transition outcomes. Under this domain, they assess needing assistance with six activities of daily living and seven instrumental activities of daily living, and measure self-rated health on a scale of 1= excellent to 4= poor (Robison, Porter, Shugrue, Kleppinger, & Lambert, 2015). It is without a doubt that health and functionality are integral to the transition process from a long-term healthcare facility to home. In transitioning individuals with TBI from long-term healthcare facility to community, this factor should be considered. Thus, a lead role for nurses in this process is strongly recommended. The use of a social model, as adopted by this initiative arguably allows for cost savings, but the health, safety, and quality of life of an individual is priceless.

### **Facility and Market Factors**

Another essential factor besides health and functionality, which needs to be considered during transitions from long-term health care facilities to the community, is the facility and market factors. Arling et al., (2011) found that both facility and market factors influence a patient's discharge from a nursing home to the community (Arling et al., 2011). The study indicated that facilities that are more Medicare-oriented, invested in

their nurse staffing, and had residents that preferred to be in the community, tend to transition more residents into the community. The same study also noted that the availability of HCBS in the community also influenced community discharges (Arling et al., 2011). A more recent study also reported that facility characteristics such as size, occupancy, ownership, the proportion of Medicare and Medicaid residents, and the proportion of residents admitted from acute care facilities are associated with discharge to the community (Holup et al., 2016). Although these studies were focused on the adult population 65 and older, these factors may also influence the transitioning of young and middle-aged individuals with TBI to the community since they also currently reside at these same facilities.

### **Environment**

In a qualitative study, Winkler et al., (2011) noted that the transition of individuals with ABI including TBI to the community is influenced significantly by environmental factors (Winkler et al., 2011). Study suggested that the environmental factors that influenced positive transition outcomes in a group home setting were: physical (facility location, availability of transportation, layout, furnishing, and interior design of facility), social (age range and compatibility of other residents in a supported living environment) and attitudinal (philosophy and milieu of the services, the level of acceptance and understanding of people with behavioral impairments). The study participants, including caregivers who had successfully transitioned from aged care facilities in Australia to the community (group home and/or other supported settings), indicated that the environment in the community allowed for more one to one care, consistency and familiarity with caregivers, and promoted respect and dignity in comparison with living in an aged care



facility (Winkler et al., 2011). Other studies have also reiterated the importance of this factor in transitioning (Leedahl et al., 2015; Park, 2012; Turner et al., 2011).

### **Barriers to Transition**

A barrier is defined as any obstacle that may hinder a smooth transition to home, and potentially cause emotional distress. These included: geographical location, lack of trained personnel, difficulty accessing services, medical complexity, lack of adequate community supports and services, caregiver strain, financial constraints, and negative societal attitudes.

Among individuals with TBI and their caregivers, lack of access as well as poor coordination and delivery of services and supports appeared to be the biggest barriers for a successful return to the community (Abrahamson et al., 2016; Cornwell et al., 2009; Keightley et al., 2011; Turner et al., 2011b). For example, the ease of accessing public transportation services often was very important to the individual with TBI due to their inability to drive after their injury. Hence, lack of transportation services often was perceived as the greatest barrier to reintegration into the community (Cornwell et al., 2009).

Other barriers, including geographical location, also impacted the transition experience of individuals with TBI and their families (Cornwell et al., 2009; Keightley et al., 2011; Turner et al., 2007). Lack of funding and resources, especially in rural areas, further increased this barrier. (Cornwell et al., 2009; Keightley et al., 2011; Turner et al., 2011). Lack of trained staff was another important barrier (Abrahamson et al., 2016; Cornwell et al., 2009; Fields, Anderson, & Dabelko-Schoeny, 2011; Reinhard, 2012;

Robison, Shugrue, Porter, Fortinsky, & Curry, 2012). The lack of direct care workers and specialized staff to help was especially difficult (Cornwell et al., 2009; Fields et al., 2011; Reinhard, 2012). Again, rural areas appeared to be those most affected by staff shortages, therefore making the return to such communities a greater challenge (Reinhard, 2012).

Negative societal attitudes also have been mentioned as barriers to transitioning to the community after TBI (Turner et al., 2011). A few studies indicated that substance abuse and mental illness also were barriers during nursing home transitions (Meador et al., 2011; Stoner & Gold, 2012). One study acknowledged that behavioral changes and other psychosocial issues posed the greatest challenge to goal attainment once individuals with brain injury transitioned to the community (Turner et al., 2011). Significantly, most of the barriers identified in this review were mostly related to the structural elements of the transition process. Thus, reiterating the importance of the structural elements to the transition process.

### **Transition Outcomes**

The process of transitioning is complex, and hence there is no one identified outcome measure for transitioning to the community. Some studies measure transition outcomes looking at discharge destinations (Arling et al., 2010; Bardo et al., 2014; Mudrazija et al., 2015; Robison et al., 2015) and rate of discharge (Gassoumis et al., 2013; Holup et al., 2016; Leedahl et al., 2015; Meador et al., 2011). Others measured transition outcome in terms of number of re-hospitalizations and emergency department (ED) visits (Park, Branch, Bulat, Vyas, & Roevers, 2013; Reidt et al., 2016; Robison et al.,

2015; Toles, Young, & Ouslander, 2012; Wysocki et al., 2014). A few, especially those focused on long-term healthcare transitions, looked at rate of re-institutionalization (Bardo et al., 2014; Robison et al., 2015) and other psychosocial outcomes such as life satisfaction (Robison et al., 2015) and community integration (Nalder, Fleming, Foster, et al., 2012). Other studies focused especially on TBI transitions to home and measured outcome in terms of functional ability and independence at home (Conneeley, 2012; Nalder, Fleming, Cornwell, & Foster, 2012; Nalder, Fleming, Cornwell, Foster, & Haines, 2012; Nalder, Fleming, Cornwell, Foster, Ownsworth, et al., 2012; Nalder et al., 2016; Winkler et al., 2011). These psychosocial outcomes align with how individuals with TBI and their caregivers perceive their transition outcome. Individuals with TBI and their family caregivers measure their outcome about normality. They conceptualize normality as return to work and driving (Abrahamson et al., 2016; Conneeley, 2012; Nalder, Fleming, Cornwell, & Foster, 2012), and being able to live and function independently and regain control over the decisions in their lives (Nalder et al., 2016; Nalder et al., 2013). In examining the factors associated with a successful transition in the first six months after discharge, a study reported that individuals with TBI associated higher levels of community integration and quality of life with transition success (Nalder et al., 2012). In that same study, they associated regaining independence in the use of transportation with a positive perception of their successful transition to the community (Nalder et al., 2012). It should be noted that a visual analog scale created by authors was used in measuring perceived transition success. The actual psychometric properties of this scale were not tested in this study and remain unknown. Therefore, findings should be noted with caution.

Transitioning outcomes for individuals with TBI have been poor due to the impact of the injury on their functional and cognitive abilities. Their injuries rob them of their independence and cause them significant emotional distress (Nalder, Fleming, Cornwell, Foster, et al., 2012). Some can regain back some, if not all, of their independence and functional abilities (Nalder et al., 2016; Winkler et al., 2011) upon transition to the community. Given that individuals with TBI and their families perceive transition success regarding psychosocial outcomes (community integration, quality of life and functional independence), it is important for nurse researchers to consider such outcome measures in future transitional studies.

### **Transition Intervention Programs**

Current intervention programs are focused on improving 30-day readmission rates, hospitalization and ED visits and rate of discharge and re-institutionalization upon transition to the community (Meador et al., 2011; Park et al., 2013; Reidt et al., 2016). A few focus on improving psychosocial well-being during transitions (Lee et al., 2016; Stoner & Gold, 2012). Considering the significant emotional distress that current transition processes impose on the individual with TBI and their caregivers, it is prudent to design studies that focus on coping strategies and community living management skills.

The Stepping Stone Program; a group-based educational program for individuals with a disability who transitioned from long-term healthcare facilities to home, could be used as a model. The program was intended to assist persons with disability to regain community living skills. The program offers ten (10) sessions and covers the following

content areas: understanding disability, knowing disability rights and advocating for them, identifying and strategizing barriers to community living (e.g. housing, transportation, finance, health and risk management), accessing information and resources for community living using a computer and building social supports and networks, and communicating effectively. Each session lasts two and one-half hours and includes mixed formats of lecture, discussion, and hands-on activities (e.g., role-playing) to increase participants' engagement and interaction. The participants attended two sessions a day (Lee et al., 2016). Overall, participants rated the program favorably, and the study showed a significant increase in their confidence regarding community living management skills. Their self-efficacy in community living management skills was found to improve as well as their sense of empowerment and confidence in finding resources and managing community living improved (Lee et al., 2016). The study was focused on individuals with a physical and psychiatric disability and was not specific to TBI. This educational program might work for individuals with TBI who preserved or have regained significant cognitive and learning ability. However, individuals who sustained severe injuries, especially to the frontal lobe, may have trouble with such an educational based program.

### **Summary**

Transitioning to the community is complicated and involves both physical and psychological processes that occur simultaneously but is uniquely linked by a myriad of factors as depicted in Figure 2. This chapter synthesized existing literature on transitions

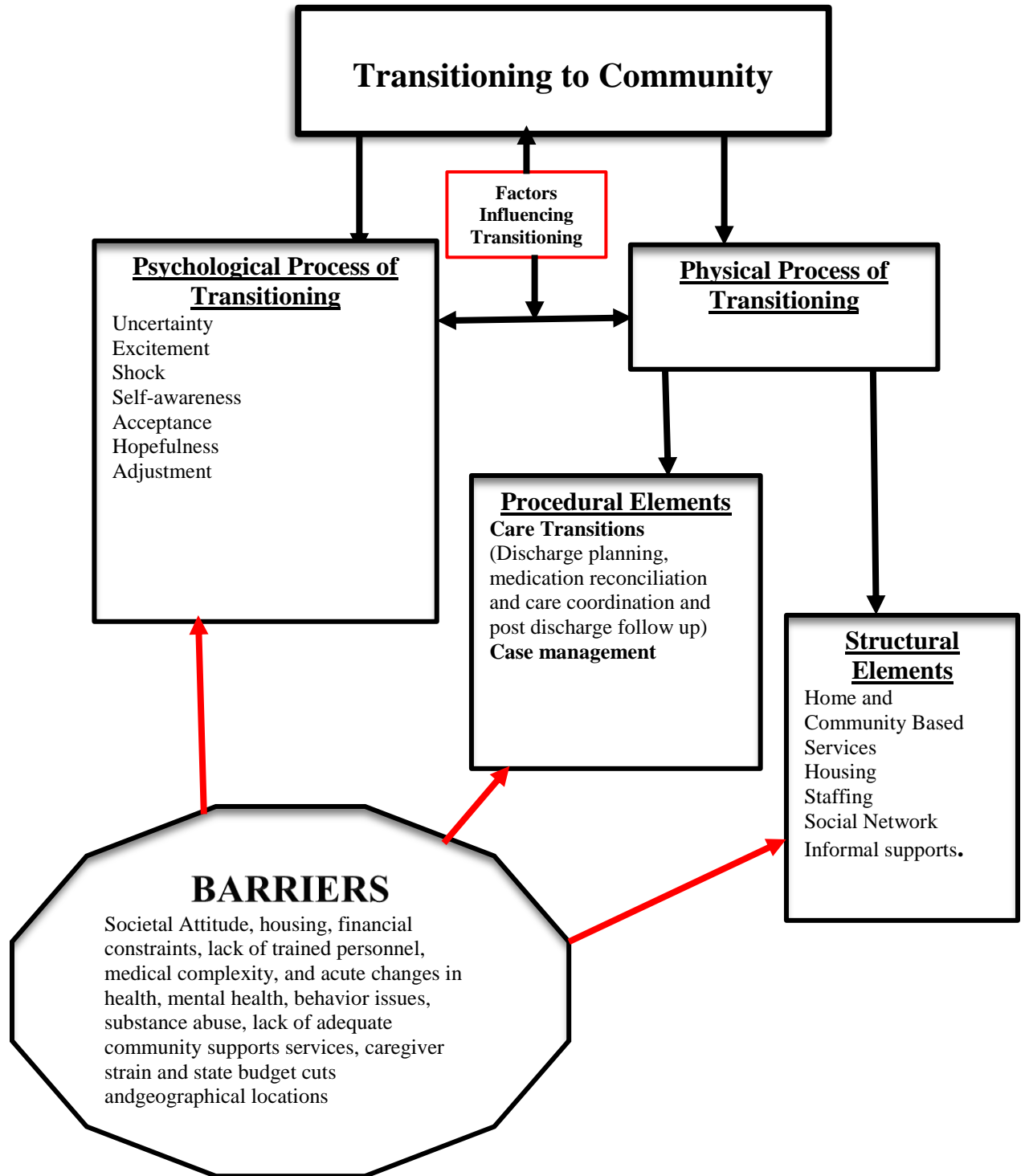


Figure 2: A model showing the process of transitioning from a healthcare setting to the community.

to the community with an emphasis on the individual with TBI and on long-term healthcare transitions. This review looked specifically at the process of transitioning to

the community, the barriers to the transitioning process, the outcome of the transition process, factors influencing the transition process, and some transition intervention programs that are in place. Transitioning to the community, as described by individuals with TBI and their family, is a continual emotional process influenced by a myriad of factors, including both elements of the physical transition process (procedural and structural). The impact transitioning has on their psychological wellbeing cannot be underestimated. This review reveals the underlining psychological processes that occur during the transition to the community, and the emotional impact suboptimal physical processes can have on the individual transitioning to the community from acute care settings. What remains unknown is whether these psychological processes also occur during transitioning from long-term care settings.

Transitioning, as is currently known in the long-term context, is a complicated physical process involving many stakeholders, including the individual and family, and is also influenced by the myriad of factors earlier indicated. At present, long-term care transitions is largely focused on the older adult population with chronic illnesses, aside from TBI, with the goal of reducing healthcare cost. Studies reviewed suggest a suboptimal process of discharge due to poor communication and coordination, and lack of knowledge of the process by staff resulting in patient dissatisfaction (Toles et al., 2016), except transitioning under Medicaid waivers. Also notable is the fact that transition outcomes have primarily been measured objectively, as in 30-day readmissions and number of ED visits. Subjective measures that focus on the psychosocial aspects such as life satisfaction, quality of life and community integration have yet to be fully explored in long-term care transitions. Despite the plethora of studies on long-term care transitions

to the community, the experiences, the process, and the outcomes of transitioning young and middle-aged individuals with TBI that also live in long-term healthcare settings are still unknown.

This review has also revealed that transitions, as studied by nurse researchers currently, look specifically at the procedural elements of care delivery, i.e., care transitions and case management of adults with chronic illnesses (excluding TBI), and mostly in the context of acute care settings. These aspects, as shown by this review, forms only a sliver of what actual transition to community entails. The structural elements of the process, as well as the entire psychological processes that occur during transitions, has so far been missed, and this may account for some of the suboptimal transition outcomes being reported (Camicia et al., 2014). To ensure a successful transition to the community, it is critical to use a comprehensive approach that incorporates both the psychological and physical (structural and procedural) aspects of transitioning. Important factors such as supports (formal and informal), health and functional ability, facility and market factors, environment, and staffing significantly influence the transition processes and should be addressed. Transition intervention programs should incorporate psychosocial supports, which are currently missing. Importantly, the lives of the individuals with TBI and their caregivers are uniquely linked, and hence to ensure their successful transition to the community, they should be considered as a unit.

Future studies are needed to specifically determine the type and quantity of support most relevant for a successful transition. Studies on the role of the nurse in the transitioning process are urgently needed. More intervention studies on transitions are



also being recommended, as this is minimal in current literature. Transition studies that focus more on psychosocial outcomes such as community integration are also being recommended here. More importantly, studies on the social processes of transitioning other populations, aside older adults from long-term care to the community, are needed. Hence, this proposed study that seeks to explore the social processes younger adults 18 years and older with TBI experience during their transitioning from long-term healthcare settings to the community is a step in the right direction.

### **The Theoretical Framework**

Grounded theory has its roots in symbolic interactionism. Thus, symbolic interactionism was used to guide this research. Symbolic interactionism is a sociological concept laid by a pragmatist George Mead in 1900 and further developed by Blumer as a sociological theory adapted for research (Jeon, 2004). Symbolic interactionism, according to Carter and Fuller (2016), addresses how society is created and maintained through repeated interactions among persons (Carter & Fuller, 2016). Meaning is central to the tenets of symbolic interactionism which postulates that: (1) human beings act based on the meanings objects have for them; (2) interaction occurs within a particular social and cultural context in which physical and social objects (persons), as well as situations, must be defined or categorized based on individual meanings; (3) meanings emerge from interactions with other individuals and with society; and (4) meanings are continuously created and recreated through interpreting processes during interaction with others (Blumer, 1969; Carter & Fuller, 2016). Charmaz further extends this premise and indicates that: 1) meanings are interpreted through shared language and communication;

2) the mediation of meaning in social interaction is distinguished by a continually emerging processual nature; and 3) the interpretative process becomes explicit when people's meaning and/or actions become problematic or their situation change (Charmaz, 2014; Charmaz, 1980). In symbolic interactionism, the use of objects such as nonverbal gestures, language, person, etc., as symbols of meaning is vital in social interactions and processes (Blumer, 1969).

Symbolic interactionism does not assume that meaning originates from an object. Instead, it assumes that people form meaning with what they do with the object. Therefore, objects may have a different meaning to different people based on their experience and/or interaction with it. Meaning can, however, be impacted as one engages in social interactions. For example, one may not truly know what it means to have a traumatic brain injury unless one sustains this injury or associates intimately with individuals who live daily with traumatic brain injury. In transitioning to the community after a traumatic brain injury, individuals were often faced with a new reality of presuming what living at home meant with their new identity (Nalder et al., 2013; Turner et al., 2011). Meaning as experienced by the individual with TBI in transition is often recreated.

Even though symbolic interactionism was developed by a pragmatist, its tenets as described, also align well with the constructivist worldview where truth is relative, and meaning is flexible (Charmaz, 2006, 2014). In constructivism, meaning is constructed when an individual engages with the world. Meaning is therefore intersubjective and perceived and constantly reinterpreted among individuals in social interactions (Carter & Fuller, 2016). Meaning and reality in constructivism are also products of individual and

collective actions. (Charmaz, 2014). Constructivists are under the assumption that people are born in cultures that have already constructed meaning about their objects and symbols, and through social interactions, the meanings these symbols hold is ultimately impacted (Licqurish & Seibold, 2011). Constructivists vision of reality as constructed creates a quest to find out how such reality is accomplished and determines what people at any particular time consider as reality, how they construct their views, and how social processes ensues (Charmaz, 2014). This view of inquiry and symbolic interactionism is congruent. Therefore, the use of a constructivist grounded theory method as proposed for this study is proper.

To explore the meaning individuals with TBI, their families, professional caregivers and community service providers associated with the process of transitioning to the community as this study aimed to accomplish, it was imperative to engage in repeated social interactions. In this study, I immersed myself in the participant's world by spending time and interacting with participants in their social settings through data collection processes and an iterative process of data analysis, as is consistent with constructive grounded theory methods. Interacting in their social world, allowed participants to impact the meanings of the symbols inherent in their everyday lives as they transition and live their life in the community. Some study participants with TBI had significant speech impairment and could hardly express themselves verbally. They also had experienced some cognitive impairments due to their injury. Therefore, I often used non-verbal gestures, facial expressions, and sounds to communicate with them and to construct the meaning of their transition experience. In many situations, I had to rely on their caregivers at the group homes, who often had years of close interaction with the

participant, to help make meaning of some peculiar sounds or expressions. The true meaning of participant's transitioning experiences was therefore obtained based on how identified objects and symbols such as language, gestures, sounds, facial expressions, and mannerisms were being defined and categorized by the individual with TBI, their family, professional caregivers, community service providers, and myself in close partnership. A partnership built through face to face interactions with study participants, as well as through indirect interaction with the data, led to the emergence of meaning inherent to the process of transitioning to the community. Thus, leading to the development of substantive grounded theory.

## **CHAPTER 3**

### **RESEARCH METHODS**

#### **Introduction**

Transitioning from healthcare settings to the community is a complicated process that involves both physical and psychological processes influenced by a myriad of factors. The goal of transitioning an individual with TBI, especially from a long-term health care facility to community, is to provide dignity, improve their quality of life, wellbeing, and community reintegration (Winkler et al., 2011). Unfortunately, very little about the process of transitioning individuals with traumatic brain injury from long-term healthcare settings to the community is known. It is therefore imperative to explore this phenomenon and develop a new theory that will guide practice. Thus, the use of grounded theory method.

This chapter will elaborate on the methodology proposed for this study. Areas covered include: research design, setting and sample, data collection, data management and analysis, and trustworthiness. At the end of the chapter, an overview of the research findings will be presented to provide readers with a glimpse of how findings will be laid out in the preceding chapters of this thesis.

## **Design of Study**

### **Constructivist Grounded Theory**

The central purpose of this research study was to develop theory. Therefore, the constructivist grounded theory method (Charmaz, 2006, 2014) used for this study was appropriate. A grounded theory provides a framework to examine social processes in a social context with the goal of developing substantive theory. Grounded theory is a systematic yet flexible method for collecting and analyzing qualitative data to construct theory (Charmaz, 2014). Grounded theory methodology provides guidelines for the construction of theory through rigorous analysis of data using an iterative process of induction, deduction, and comparisons.

Glaser and Strauss developed grounded theory in 1967 (Glaser & Strauss, 1967). However, through the years, grounded theory has evolved based on differences in the ontological and epistemological perspectives of the originators of the method. Glaser, from a positivist background, assumed an external reality; assumed discovering of data and the neutrality of the researcher (Charmaz, 2014). He was of the view that a theory could be developed logically and systematically, explicating specific strategies for conducting qualitative research (Hall, Griffiths, & McKenna, 2013). On the other hand, Strauss was a pragmatist who believed that truth was multiple and subjective, and meaning relied on the use of language and emerged through action (Charmaz, 2014; Hall et al., 2013; Higginbottom & Lauridsen, 2014). Despite their different ontological views, they collaborated and defined grounded theory methods for qualitative research. Their differences in epistemology will later cause a divergence in their approach to conduct grounded theory. Glaser remained consistent with his initial approach to grounded theory

as a method of discovery where categories emerged from the data, and the researcher was a passive and neutral actor (Charmaz, 2006, 2014).

On the other hand, Strauss, and later in partnership with Corbin, moved away from this original approach and considered the grounded theory as a method of verification (Cooney, 2010; Corbin & Strauss, 2015; Higginbottom & Lauridsen, 2014). This method received criticism for its technicality and complexity in categorizing and describing data (Charmaz, 2006; Cooney, 2010). The rigidity of this method shifted away from the flexibility of the pragmatist position. In her recent writing, however, Corbin appears to encourage flexibility as she leans more towards constructivism (Corbin & Strauss, 2015). Charmaz, in an attempt to bridge the two positions, initially developed the constructivist grounded theory method that turns to answer the numerous criticisms raised over the years (Charmaz, 2014). This method adopts the inductive, comparative, emergent, and open-ended approach of Glaser and Strauss (Glaser & Strauss, 1967), and incorporates the iterative logic and the emphasis of action and meaning consistent with pragmatism (Charmaz, 2014). This method, however, highlights the flexibility of grounded theory, embraces the subjectivity of qualitative research and, most importantly, fosters an integral role for the researcher. Furthermore, this method takes a constructivist perspective and contends that social reality is multiple, processual, and constructed such that the researcher's perspective, privilege, and experiences are critical to the construction of meaning (Charmaz, 2014). Also, the constructivist grounded theory method creates "theory that has credibility, originality, resonance, and usefulness" (Charmaz, 2014). It aims for interpretative understandings of historically situated data

and also seeks and represents the voices and opinions of participants throughout its data analysis process (Charmaz, 2014).

Amidst these drifts in approaches, the core elements of grounded theory, such as conducting data collection and analysis simultaneously in an iterative process, using comparative methods, drawing on data to develop new conceptual categories, theoretical sampling, and systematic analysis of data still are true to all three methods. The decision to choose one methodology over the other is mostly dependent on one's ontological and epistemological view.

In this study, the author used a constructivist approach in conducting grounded theory due to the researchers' belief in the flexibility and subjective method of constructing meaning. As an immigrant who has experienced transitions first hand and as a nurse with tremendous experience working with and fostering the transitions of individuals with TBI to the community, this method was a great fit. This choice is also because my past and present interactions with the individuals with TBI and their families allowed for intimacy and fostered a shared trust among myself and the participants. This trust led to an authentic relationship and encouraged a strong bond that helped impact the true meaning of their experiences and, subsequently, led to the construction of substantive grounded theory.

In this study, I closely followed the core techniques of a constructivist grounded theory methodology (Charmaz, 2006). First, I came up with a research question that identified the phenomenon to be studied. My research question is: What are the social processes involved in transitioning adults (18-65 years) with TBI from long-term healthcare facilities to the community? The central phenomenon under study was



“transitioning to the community.” The purpose of the grounded theory was about discovery and classic grounded theorists strongly advocate the delay of literature review until after the completion of the analysis (Charmaz, 2014). This view prevents the researcher from viewing his/her data through the lens of earlier ideas obtained through prior review of existing literature. Despite this consideration, I conducted an extensive survey of the literature before and after data analysis, as I recognized that pretense on my part of a lack of familiarity with the research and with the transition process is untenable, given my years of experience in working to transition individuals with TBI to the community. Also, given the fact that I had to conduct literature reviews on this phenomenon as a requirement for several papers throughout my doctoral study and my dissertation, I had no choice but to embrace the use of such in-depth knowledge from the review of the literature to identify gaps in the research, clarify my ideas, make comparisons, and to help show how my work of study fits or extends the relevant literature. Prior knowledge of the literature also enabled me to be theoretically sensitive to my data, as I was able to identify and understand some concepts or phenomenon as they emerged during the study. At the same time, I was mindful of my inherent biases, and I used reflectivity, memo writing, and member checking to stay close to the data throughout the analysis of data and the development of theory. Also, as a constructivist, this prior review of the literature, as well as my perspective, privilege, and experiences, were critical to the construction of meaning during theory development. The process of data collection and data analysis was done simultaneously, and theoretical sampling was employed throughout this study. That is, as I collected my data, I coded and analyzed them immediately after transcription to decide what data to collect next and where to find

it, while continuously generating new questions. Finally, I employed the core concepts of data analysis as required in constructivist grounded theory methods, which included initial, focused, and theoretical coding methods, constant comparison techniques, memo writing, and reflectivity, as depicted in Figure 3 and elaborated in the data analysis section below. I also kept an audit trail by keeping an activity log and using Nvivo 11 software.

## **Setting and Sampling**

### **Setting**

Study participants were recruited from approved residential group homes for ABI/MFP waiver participants, including individuals with TBI across the Commonwealth of Massachusetts. These residential group homes are dispersed in towns around the Commonwealth. The homes are privately owned but regulated by the Executive Office of Health and Human Services (EOHHS) in conjunction with the Department of Developmental Services (DDS). These residential group homes have no more than four residents living there at any time. These homes are handicapped accessible and are not exclusive to individuals with TBI, and often include individuals with other acquired brain injuries. These homes are staffed to provide care and oversight to their residents 24 hours a day, seven days per week. Many of these homes make provision for oversight nursing hours up to twelve hours during the day, and a few provide round the clock nursing services, as they tend to have more medically complex residents. Families and friends visit at any time but are not allowed to live in residence. Individuals with TBI and residential program directors and staff who participated in this study lived or worked in

such homes located in Dartmouth, West Wareham, Rochester, South Hardly and Amherst.

### **Sample**

The research sample for this study included individuals with TBI, family caregivers, professional care providers (service coordinators, social workers, and occupational therapist), and community services providers. Community service providers included residential program directors and staff, community-based therapists from the Massachusetts Association for the Blind (MAB), and director and transitioning coordinators from Northeast Independent Living Inc. (NILP)). Following Institutional Review Board (IRB) approval, I used purposeful sampling to find some participants, during the initial stage of the research, who could readily articulate their experience of the transition process to help move the research forward. The initial use of purposeful sampling in grounded theory has been found to be useful (Burns & Grove, 2007). Theoretical sampling was subsequently employed, as was inherent to the constructivist grounded theory methods.

### **Theoretical Sampling**

Theoretical sampling is a process of data collection whereby the researcher simultaneously collects, codes, and analyses his/her data and decides which data to collect next and where to find the data. (Currie, 2009). A researcher engaging in theoretical sampling aims to develop the properties of his/her developing categories or theory (Charmaz, 2014). Charmaz suggests that when using theoretical sampling, the

researcher should seek people, events, or information to illuminate the properties and boundaries of an emerging category (Charmaz, 2014). In keeping faithful to this inherent requirement of grounded theory, the emerging concepts and categories drove the sampling for this study. Sampling continued until theoretical saturation was reached. Theoretical saturation occurred when I determined that all relationships between categories were checked and defined, without the establishment of new properties of these categories, as suggested in constructive grounded theory methods (Charmaz, 2014).

### **Sample Size**

In a grounded theory study, sampling is flexible, and it is often difficult to predetermine the sample size of the study as it is determined by the emerging theoretical framework. Charmaz (2014) recommends choosing a sample size that is not so small as to engender skepticism about results, and not so large as to make excessive data an impediment to analysis, but enough to develop new categories and create a credible analysis (Charmaz, 2014). Study anticipated the selection of about thirty-five (35) study participants who are directly involved in the transition process. The actual sample recruited for this study, however, was thirty-one ( $n=31$ ), comprising of three (3) individuals with TBI, three (3) family caregivers, fifteen (15) professional care providers and ten (10) community-based service providers. The 15 professional care providers include ten (10) service coordinators from DDS, and four (4) social workers from long-term nursing facilities in Massachusetts and one (1) nurse from DDS. The ten (10) community-based service providers comprised of two (2) residential program directors

and one (1) residential program staff, five (5) occupational therapists from MAB, and three (3) transition coordinators from Northeast Independent Living Program Inc.

Table 2: Summary of study sample and size.

Sample	Sample size
<b>Individual with TBI</b>	<b>n=3</b>
<b>Family Caregiver</b>	<b>n=3</b>
<b>Professional Caregiver</b>	<b>n=15</b>
• DDS service coordinators	n=10
• Social workers	n=4
• DDS registered nurse	n=1
<b>Community Service Providers</b>	<b>n=10</b>
• Residential program directors	n=2
• Residential program staff	n=1
• Community-based occupational therapists	n=4
• Transition coordinators	n=3
<b>Total</b>	<b>n=31</b>

### Sample Criteria

**Participant as Individual with TBI.** All participants met a set criterion required for this study. Individuals with TBI were adults 18-65 years or older who had sustained a traumatic brain injury as an adult (18 years or older), lived at least 90 days in a long-term healthcare setting, and had transitioned to a waiver approved group home setting within the Commonwealth of Massachusetts. Individuals selected were capable and willing to provide consent, or had a guardian involved who was willing to consent to his/her participation in the study. The ability for the individual with TBI to speak and understand English and participate in an interview was preferred, but not required. Individuals with TBI who participated in this study were screened for mental status using the Mental

Status Questionnaire (Kahn et al., 1983). The Mental Status Questionnaire (MSQ) provides a brief, objective, and quantitative measurement of cognitive functioning. The MSQ has ten items taken from existing mental status examinations and clinical experience. The questions cover orientation in time and place, remote memory, and general knowledge. The MSQ reports a Cronbach alpha of 0.81. The MSQ score counts the number of errors; a score of 0 is ideal, with omissions considered as errors. The MSQ proposes groups based on the severity of chronic brain syndrome classified by the number of errors made: 0-2 errors-none or minimal; 3-8 errors-moderate; 9 or 10 errors-severe. Even though the MSQ is used and tested mostly with an older adult population, its simplicity and ease of administration were considered appropriate for use in this study as a quick screening tool to help the researcher determine the method suitable for data collection. Individuals who scored in the moderate to severe range on the MSQ were observed and not interviewed due to their significant cognitive impairment. Non-verbal individuals with TBI, and those noted to have significant communication difficulties, underwent observation but were not required to participate in an interview unless they opted to do so.

**Participant as Family Caregiver.** Family caregivers who participated in this study were adults 18 years and older. They were either family or a close friend to the individual with TBI and had been closely involved with the individual since his/her stay at the long-term healthcare facility, up until his/her transition to the community, and provided all needed supports. Family caregivers spoke and understood English, and willingly gave consent to participate in an interview.

**Participant as a Professional Caregiver.** Professional caregivers were adult 18 years or older, worked at or were affiliated with a selected ABI/MFP waiver approved group home setting, and worked closely with the individuals with TBI during their transition to the community. Professional caregivers identified with a professional body and institution. All participants spoke fluent English and were able and willing to consent to participate in an interview.

**Participant as a Community Service Provider.** The community service providers were adults 18 years or older who owned or were employed by a community service agency affiliated with the ABI/MFP waiver program in the Commonwealth of Massachusetts. The community service providers who were recruited to take part in this study had to have some knowledge and be involved with the everyday activities at the agency and with the individual with TBI. These providers were expected to be fluent in the English language and able and willing to participate in an interview.

### **The Recruitment Process**

The recruitment of participants for this study was a very arduous process, as it involved dealing with different levels of bureaucracy to obtain approval to investigate such a vulnerable population. I anticipated this problem, and as such, to gain access and ensure a smooth process, I made a deliberate attempt to establish appropriate relationships with key personnel at the state agencies. As an employee of one of the affiliated agencies, I quickly gained the trust of my superiors. My intent to study this population was made known to the director of the ABI/MFP Medicaid waiver program at

the Executive office of the Health and Human Services (EOHHS) and the director overseeing the ABI/MFP waiver program at the Department of Developmental Services (DDS). Despite their approval for such a study, it was difficult to ascertain which agency was directly responsible for providing a formal approval for a study involving waiver participants. Further complicating this was the underlying fact that the participants of the ABI waiver program, who made up most of my desired sample, were also plaintiffs in a case involving the state. The ABI waiver program was initially developed as part of a legal settlement (Hutchinson v. Patrick, 2008). Therefore, there seemed to be some apprehension by the agencies regarding such a study. The other problem was that DDS had direct oversight of participants living in these ABI/MFP residential homes and provided case management services to them in the residential homes. Their Institutional Review Board (IRB), on the other hand, only reviewed studies specific to individuals with intellectual disability (ID) and/or developmental disabilities (DD), and not the acquired brain injury (ABI), including TBI population. Even though I was asked explicitly to send an application to the DDS IRB for review, I received a letter on 7/23/17 indicating that it was not necessary for this study as participants were not ID/DD (see Appendix C). It was therefore agreed upon by the head of the waiver program at DDS for me to proceed, given that I had already obtained approval from the Institutional Review Board (IRB) at the University of Massachusetts Amherst since June 20th, 2017.

### **Recruitment of DDS Service Coordinators**

Once all proper approvals were obtained, I directly contacted the supervisor of all the DDS service coordinators by phone to ask for a copy of their contact list of all their



service coordinators. After about a week of waiting, I received an email on 8/8/17 to contact the Community Systems Director in each of the four DDS regions so they could help with obtaining such a list, which I did. The community systems directors, in turn, sent emails to all of their service coordinators to inform them that I was going to be contacting them for a study, if they were willing to participate. I started to receive emails and calls from some service coordinators who were interested in taking part in the study. I also received a list of names from some of the community systems directors of staff willing to take part. I then made either a phone call or sent an email out to the interested individual to explain further what the study was about and to solicit their participation, guidance, and help in identifying some individuals with TBI on their caseloads who could also potentially participate in the study. Interviews with the service coordinators were scheduled at a date and location of their convenience.

The decision was made to first solicit the participation of the DDS service coordinators, because they were key players in managing and coordinating the transition process. They also work very closely with all the stakeholders involved in the process, including the individual with TBI, their family caregivers, group home staff, and other community service providers, and have done so over the years. The long-standing relationships these service coordinators have with waiver participants and all the stakeholders made them very valuable gatekeepers to this study.

### **Recruitment of Individual with TBI and /or Guardian**

Once a potential study participant had been identified with the guidance of the DDS service coordinator, a phone call was placed directly to the individual with TBI or

to the guardian, if one was involved. The family caregiver involved was also informed about the research study and invited to participate in the study as well. In this study, some of the family members that participated were also the assigned legal guardian. Once a participant was identified, the management of the residential homes was also informed by the DDS service coordinators about the study. When the individual with TBI or guardian agreed to participate, I placed a follow-up phone call to the residential director of the home to inform them of the participant's decision. I took the opportunity to explain further what the study was going to be about and ask for their support in making all the needed arrangements for the study to proceed (see Appendix D). A convenient day and time for observation and interview of the participant were then scheduled. All the group homes involved were very receptive to the study and provided full access to their facility and staff.

### **Recruitment of Family Caregiver**

Family caregivers were informed about the study once an individual with TBI was identified as a potential participant. In many instances, these family caregivers were also the assigned guardians, and hence their recruitment was concurrent with that of the individual with TBI. However, their interviews were scheduled at a different time and location, and were always at their convenience.

### **Recruitment of Residential Staff**

The study recruited residential directors and staff as it progressed. With my repeated visits to the home to meet and observe the individual with TBI, I established

relationships with the director and staff of the residential homes and directly solicited their participation in person. Upon their agreement, convenient times and dates were then scheduled for them to interview.

### **Recruitment of Social Workers**

To recruit social workers from long-term care facilities, I distributed flyers to social workers at facilities identified to work closely with the waiver program. A follow-up phone call was often placed to solicit their participation directly. Upon their agreement, a convenient time and date were then scheduled for them to interview.

### **Recruitment of Other Participants**

As the study progressed, I identified other individuals that could inform the research and help develop emerging concepts and categories consistent with grounded theory methods. For example, transition coordinators from North East Independent Living Program Inc., who help in coordinating some aspects of the transition, as well as community-based occupational therapists from Massachusetts Association for the Blind MAB, who provide therapy services to the participants in the homes. For these individuals, I directly solicited their participation via a phone call, as I often received their contact information from my interviewees. We settled on a date, time, and location of their convenience for an interview once they agreed to participate in the study.

## Study Participants

### Individual with TBI

Three individuals with TBI participated in the study, and they met the sampling criteria as outlined above. Two of the three individuals with TBI recruited had a legal guardian in place, who provided their consent for the study. Approval was also received from the individual with TBI. The third individual with TBI who took part, acted on his own behalf, and he gave consent at his will. This individual had no family member participating in the study. Individuals with TBI participated either in an interview, observation, or both, depending on their score on the mental status screen tool (Kahn et al., 1983) (Appendix F) and the extent of their speech impairment, if any. Demographic information was obtained from all participants at the time of their interview or observation (See Appendix G). All participants received a 20-dollar gift card as a token of my appreciation.

Table 3: Demographic data for individual with TBI.

Pseudonym	Age (Years)	Year of Traumatic Brain Injury	Cause of Traumatic Brain Injury	Gender	Race/Ethnicity	Educational Level	Marital Status
Dave	58	2010	Fall	Male	White (Non-Hispanic)	High School	Widow
Chaos	30	2009	Assault	Male	White (Non-Hispanic)	High School	Single-Never Married
Butch	70	1994	Assault	Male	White (Non-Hispanic)	8 <sup>th</sup> grade	Divorced

### **Family Caregivers**

Three family caregivers participated in the study, and they also met the set criteria earlier indicated. Two of the family caregivers were related to the individual with TBI participating in the study. One family caregiver joined alone because the individual with TBI fell ill and was no longer able to participate. Written consent was received from all the family caregivers, and demographic information was obtained at the time of interview using the demographic questionnaire (See Appendix G). Each participant received a 20-dollar gift card as a token of my appreciation.

Table 4: Demographic data for family caregiver.

Pseudonym	Age (years)	Year/ Cause of TBI	Relationship to ITBI	Gender	Race/ Ethnicity	Educational level	Marital status
Glinda	57	2009/Assault	Mother	Female	White (Non-Hispanic)	High School	Divorced
Mary	63	1976/ Motor Vehicle Accident	Sister	Female	White (Non-Hispanic)	Some college	Married
Chossey	39	1994/Assault	Daughter	Female	White (Non-Hispanic)	Some college	Married

### **Professional Caregivers**

Fifteen professional caregivers participated in this study, including ten (10) service coordinators from DDS, one (1) nurse from DDS, and four (4) social workers recruited from four long-term care facilities with the Commonwealth of Massachusetts. Written consent was obtained from each participant before a scheduled interview, and each participant was also asked to complete a demographic questionnaire (see Appendix G). Each participant received a 20-dollar gift card as a token of my appreciation.

Table 5: Demographic data for professional caregivers.

Pseudonym	Age (Years)	Gender	Race /Ethnicity	Educational level	Profession /Occupation	Length of years working with organization	Number of years worked with TBI
Jessica	30	Female	White (non-Hispanic)	Bachelors	Service coordinator	1-5 years	10 years
Sue Smith	49	Female	White (non-Hispanic)	Some college	Human Services coordinator	1-5 years	10 Years
Ubda	47	Male	Black /African	Graduate Degree	Service coordinator	1-5 years	5 years
Red Sox	47	Male	Hispanic	Bachelors	Service coordinator	1-5 years	12 years
Rudy	30	Male	Hispanic	Graduate degree	Service coordinator	1-5 years	1 year
Sue White	38	Female	White (Non-Hispanic)	Bachelors	Service coordinator	1-5 years	12 years
Antonia	42	Female	Black /African	Bachelors	Service coordinator	1-5 years	4 years
Chip	46	Male	White (Non-Hispanic)	Graduate degree	Human Service coordinator	<1 year	22 years
Cassandra	32	Female	White (Non-Hispanic)	Bachelors	Human Service coordinator	1-5 years	6 years
Tina Marie	33	Female	Black /African	Bachelors	Social Worker	1-5 years	<1year
Ava	46	Female	White (Non-Hispanic)	Graduate degree	Social worker	1-5 years	25 years
Nicole	28	Female	White (Non-Hispanic)	Graduate Degree	Social Worker	1-5 years	3 years
Rickie	37	Female	Asian	Graduate	Social Worker	1-5 years	5 years
Rose Quartz	50	Female	White (Non-Hispanic)	Bachelors	Social worker	> 5 years	13 years
Kandi	33	Female	Black /African	Graduate	Nurse	1-5 years	10 years

## **Community Service Providers**

Ten community service providers participated in this study, including two (2) residential program directors, one (1) residential direct care staff, three (3) transition coordinators, and four (4) community- based occupational therapists working with the individual with TBI in the residential homes.

Table 6: Demographic data for community service providers.

Pseudonym	Age (Years)	Gender	Race /Ethnicity	Education	Profession /occupation	Length of years worked with organization	Number of years worked with TBI
Joe Smith	50	Male	White (Non- Hispanic)	Some college	Residential Director	>5 years	5+ years
Elizabeth Hapgood	36	Female	White (Non- Hispanic)	Graduate degree	Occupational Therapist	1-5 years	15 years
Alyssa Detroit	32	Female	White (Non- Hispanic)	Graduate degree	Occupational Therapist	1-5 years	8 years
Dee	60	Female	White (Non- Hispanic)	Graduate Degree	Occupational Therapist	1-5 years	5-6 years
Isadora	46	Female	Other	Graduate degree	Occupational Therapist	1-5years	< 1year
Caitlyn	37	Female	White (Non- Hispanic)	Some college	Residential Manager	>5 years	2 years
Crystal	29	Female	White (Non- Hispanic)	Some college	Residential Care assistant	>5years	5 years
Summer	44	Female	White (Non- Hispanic)	Bachelors	Human Services	1-5 years	4+ years
Kennedy	36	Female	White (Non- Hispanic)	Bachelors	Human Services	1-5 years	3 years
Luz Marie	66	Female	Hispanic	Graduate	Human Services	>5years	7 years

Each participant gave written consent before his/her participation in the study and completed a demographic questionnaire (See Appendix G). Each participant was given a 20-dollar gift card as a token of my appreciation.

### **Data Collection**

Data collection in grounded theory is an iterative process, which unfolds with the progression of the study. Gathering rich data is key to generating strongly grounded theories (Charmaz, 2014). In this study, rich data was collected using intensive interviews, observation, document reviews, and researcher- created field notes. The use of multiple tools in collecting data allowed for triangulation, further discussed in this chapter. The plan for data collection employed during the study is as depicted in Figure 3 below.

#### **Intensive Interviews**

Interviews were one of the primary means of data collection in this study. Interviewing allows for free-flowing open-ended discussions and also makes room for in-depth inquiry into social and personal issues (DiCicco-Bloom & Crabtree, 2006). Charmaz suggests the use of intensive interviewing. Intensive interviewing explores a participant's perspective on their personal experience with the research topic and creates an interactional space (Charmaz, 2014). The critical characteristics identified with intensive interviewing are: 1) selection of research participants who have firsthand experience that fits the research topic; 2) in-depth exploration of participant experience and situations; 3) reliance on open-ended questions; 4) objective of obtaining detail responses; 5) places emphasis on understanding the research participant's perspective,



meaning and experience; and 6) practice of following up on unanticipated areas of inquiry hints and implicit views and accounts of actions (Charmaz, 2014). During intensive interviewing, the social and cultural context of the participant is respected (Charmaz, 2014). This study used this intensive interview strategy, since it combined flexibility and control, allowed for social interaction and intimacy, as well as follow-ups on ideas and issues essential for co-construction of meaning. Since method was flexible, it allowed me to adjust questioning as appropriate, since its intensity seemed to pose problems for some individuals with traumatic brain injury interviewed for this study. I perceived their difficulty as due to reduced attention span and some impulsivity, and to slow processing of information. For this population, researcher adopted a more semi-structured approach. Interviews were audio recorded, and consent obtained before all interview sessions. Consistent with constructive grounded theory, follow-up interviews were scheduled and conducted as concepts emerged throughout the study.

### **Interview with Individual with TBI**

Interviewing individuals with TBI can be particularly challenging. Therefore, researchers are encouraged to accommodate and adapt to enable meaningful participation, including modifying data collection procedures where necessary (Mactavish, Mahon, & Lutfiyya, 2000). Limited guidelines currently exist for interviewing this specific population, yet there are some established guidelines for interviewing individuals with intellectual disabilities, which was modified to this population (Caldwell, 2014; Mactavish et al., 2000). It should be noted here that individuals with traumatic brain injury are distinctively different from individuals with

intellectual disability. Nonetheless, they do sometimes exhibit some unique similarity in their level of cognitive functioning. Therefore, some current guidelines that exist for interviewing individuals with an intellectual disability were adapted and modified, as appropriate, for use during this study.

Current guidelines suggest that the researcher takes into consideration the venue, the opening of the interview, question style, and question format (Prosser & Bromley, 2012) It is essential for the researcher to open the conversation by taking time to build rapport and trust and not jump immediately into the interview. It is also recommended that the interview is spread over two or more sessions to relieve pressure on both the participant and researcher.

To be mindful of such accommodations, I visited with participants for about 20 minutes to introduce myself and establish some rapport and trust. This visit was done before setting an actual date and time for interviewing. During my interviews with them, I often paused and repeated my questions to ensure clear understanding. Even though interview questions were formulated at or less than an 8th-grade level, I had to sometimes adopt a much more straightforward language fit for a 3rd or 4th grade level. I sometimes had to use slang to help them understand my line of questioning. To minimize fatigue, I conducted interviews over multiple visits of two to three with a duration of up to twenty minutes per session. Interviews were conducted in their residential homes setting, since it was familiar and comfortable to them. Follow -up meetings were scheduled and held as needed throughout the study. Before the interview, either their consents, assent, or both, were obtained from them or their guardians. They were also asked to complete a HIPAA authorization form (See Appendix J). Demographic information was collected as well,

using the demographic questionnaire (See Appendix G). All interviews were audio recorded with their consent and later transcribed for analysis. The consent form for the individual with TBI, as well as the assent form and the interview schedule, can be found in Appendix H, I and K, respectively.

### **Interview with Family Caregiver**

Family caregivers were interviewed for up to an hour using intense interviewing strategies to get to the core understanding of their experiences. Appropriate follow-up questions were often raised to help solicit rich data. The interview was always conducted in person at an agreed upon location convenient to both the participant and researcher. Written consent was obtained before the interview session. All interviews were audio recorded with their consent. Demographic information was also obtained before the start of the interview. Follow-up meetings were conducted as needed, and with the emerging of concepts during data analysis. These follow-up interviews were often done over the phone with their verbal consents. The consent form for the caregiver and the interview schedule can be found in Appendix H and Appendix K, respectively.

### **Interview with Professional Caregiver**

Professional caregivers, including service coordinators and social workers identified as directly involved in the process of transitioning of an individual with TBI, were also interviewed as part of this study. I used an intensive interview strategy, like that for the family caregivers. Again, this was to obtain rich data and to get to the core understanding of their experiences. Interviews with professionals were at an agreed time

and were mostly conducted at their place of work. Interviews were up to an hour and were audio recorded with their consent. Before the interviews, written consents were always obtained, together with their demographic information. Follow- up interviews were also conducted, as needed, to explore further the emerging concepts that unfolded during the analysis of the data. These follow- up interviews were often done over the phone or via email. These interviews were not audio recorded, but I took detailed notes. See Consents for the Professional Caregiver and Interview Schedule (Appendix H and K).

### **Interview with Community Service Providers**

Finally, interviews were done with the community service providers at an agreed time and location convenient to both participant and myself. I obtained written consent from each participant before the start of the interview, as well as their demographic information. Interviews lasted about an hour, and they were all audio recorded with their prior consent. I used intensive interviewing strategies, as earlier described. Follow- up interviews were conducted as needed and as emerging concepts unfolded during data analysis. Refer to appendix G for the Demographic Questionnaire, Appendix H for Consent for Community Service Providers and Appendix K for Interview Schedule.

### **Observation**

The use of observation in this study as a data collection tool was particularly important, since some of the individuals with TBI had significant speech and cognitive impairments and could not adequately express themselves. Therefore, through the observation of their daily interactions, behaviors, and reactions with the professional

staff, peers and their family caregiver, as well as my social interactions with them, I was able to construct the meaning they associated with their transition experience. Johnson et al. (2011) found in a study that participant observation, although time-consuming, ensures a deeper understanding of a phenomenon and provides new meaning, especially in under-researched areas (Johnson, Douglas, Bigby, & Iacono, 2011). Furthermore, using participant observation as a tool helps reveal new knowledge in people with limited formal communication skills and cognitive impairment (Johnson et al., 2011) and was true in this study. Charmaz suggests that observation with sustained participation, as practiced in ethnography, means more than participant observation alone (Charmaz, 2014) and this idea was carried out throughout this study.

### **Individual with TBI Observation**

In this study, the daily activities and social interactions of participants were observed and documented. I visited participants on several occasions to spend quality time with them by participating in their social activities, such as watching their TV shows with them, talking to them, and having coffee with them, while also observing their interaction with the staff in the home and their peers. On a few occasions, I also got the opportunity to observe participants interact with their families who had come to spend time with them. During the observation sessions, I asked the participant or staff about things happening, if I had any queries. I conducted observations at their residential homes. I also intended to observe them at their identified day programs, but unfortunately none of the study participants attended day programs. Observations were done in 1 to 2-hour sessions. Up to three sessions were done with each participant at different times of

day and on separate occasions. Consents were obtained before each observation session. See Appendix L for Participant Observation Schedule.

### **Staff Observation**

I also explicitly observed staff interaction with the individual with TBI at the residential home in this study. This observation occurred concurrently with the observation of the individual with TBI. Staff regularly interacted with the participant under consideration, as they take care of their needs 24 hours a day; 7 days a week. I met different staff every time I went in to visit with participants, since I went at different times of the day, which often coincided with the various shifts run at the home. To obtain their consents, I always met with everyone in the house at the time of my visit to explain why I was there, what I expected from them, and what I was going to be doing that day with the participants and with them. I then asked for their verbal consent to observe them, talk to them, ask questions, and use my findings to inform my study. Staff was always willing to be part of the study, and they participated fully.

### **Document Review**

Review of documents was conducted as part of data collection using a prior self-developed document review guideline (See Appendix M). Document review provided access to events that could otherwise not be observed. In this study, participant notes from the residential home staff and their individual service plans were reviewed with prior consent and HIPPA release. In some instances, these documents had protected health information, thus they were examined on site and information extracted as notes.

The notes generated were then de-identified. I also obtained and reviewed forms and protocols used by the DDS service coordinators during the transition process. I also reviewed my journal entries and field notes as part of data collection. This method helped supplement data obtained from the interviews and observation sessions, which further enhanced the rigor of the study. The use of existing documents in qualitative research is valuable and serves as a communication tool between the social world and its actors, and helped generate meaning (Miller & Alvarado, 2005). Information obtained was often explored further through discussions and follow-up interviews. Consent for release of medical records was obtained as appropriate and per HIPAA regulations (See Appendix J).

### **Field Notes**

After each session of data collection, I wrote, or audio recorded my field notes to document my observations. According to Charmaz, a field note may record individual and collective actions, and contain full detailed notes with anecdotes and observations. It also emphasizes important processes occurring at the setting, (consider participant language use, place actors and actions in scenes and context), and may address what participants define as interesting and/or problematic (Charmaz, 2014). My field notes or recordings were detailed and gave an account of the environment, what was observed and heard, my reflections of the day, and the specific activity conducted, be it an interview or an observation session. The field notes generated in this study was considered as actual data and analyzed as part of theory construction.

## **Protection of Human Subjects**

I (the researcher) completed the Collaborative Institutional Training Initiative (CITI) training in September 2014 (Appendix R). Approval for the use of human subjects was sought and obtained from the Institutional Review Board (IRB) at the University of Massachusetts Amherst on June 20th, 2017. An application for the use of human subjects was also sought from the IRB at the Department of Developmental Services, but I received a letter on July 23rd, 2017 to indicate that such a review was not needed for this study, as participants were not ID/DD. All study participants provided written and verbal consents and had, in some cases, provided assent under the principles of full-disclosure. Participants also received copies of their signed consents. This study upheld the standard principle of human protection and participants were given the right and option to reject, withdraw, or stop an observation or interview if they chose to, with no repercussions. In conducting the study, I was sensitive to participants' emotions. I acknowledged that for the individual with TBI and their families, the events leading to their injury was traumatic and interviewing could bring up past emotional memories. As a result, I put in place a protocol to mitigate such emotional distress, if it should arise (See Appendix P). A protocol was also put in place to mitigate any inappropriate behaviors that could arise during interactions with the individual with TBI (See Appendix O). Each individual with TBI and family caregivers were also given a list of organizations in the community that could provide added emotional supports in case of any emotional distress caused by participating in this study (See Appendix Q). However, throughout the study, there was no evidence or report of emotional distress by study participants.



To further protect the privacy and confidentiality of the participants in this study, a pseudonym chosen by the participant was used for all transcripts of interviews, field notes, and for identifying recordings and extracted notes from documents reviewed. Participants were provided the option of checking transcripts to ensure that it reflected their meaning, and to correct any misrepresentations. Information was presented to them in a summary form. Participants were not identified in any presentations or publication. Demographic information and signed consents were kept in a locked cabinet. Research records were labeled with a code, and a document linking the names and codes was maintained in a separate and secure location. Audio recorded interviews were stored as MP3 files, and de-identified e-files of transcripts for each participant stored in Nvivo software on a password-protected computer. Only the researcher had access to the password and data. When researchers publish and present their findings, participants and any events or experiences that could potentially identify them, will be de-identified, including workplace and group home setting. Audio recordings will also be destroyed after the study.

### **The Role of the Researcher**

The researcher is regarded as the lens in a grounded theory study through which data is gathered and interpreted. Some school of thought perceive that the researcher plays a very neutral role, as to avoid the biases in data collection and further its interpretation, and to present the unbiased result of the study (Glaser, Strauss, & Strutzel, 1968). Researchers, however, hardly exist in a bubble, and are often influenced by their experiences and perceptions hence, neutrality cannot be fully achieved. Therefore, in

using the constructivist approach, I embraced the subjectivity of my role as a researcher in constructing grounded theory. As postulated by Charmaz, researchers construct grounded theories through their past and present interactions with people, their perspectives, and their research (Charmaz, 2014). Despite this, I was mindful of my biases and continuously engaged in reflectivity to ensure that the meaning constructed in this study represented entirely that of the participants.

Throughout this study, I remained sensitive to the emerging concepts and phenomenon, and closely interacted with my participants as I developed their trust through partnership. They welcomed me into their world and helped me to understand their meaning of the phenomenon of transitioning to the community. I asked questions, carried out informal conversations with them, watched TV with them, and had tea with them. I also read about them in reviewing the individual service plans for the participant with TBI and observed their daily activities of living in a residential group home setting.

### **Data Management**

Data for this study included individual interview transcripts, photographic data, general documents about transition process (including organizational protocols and forms), notes extracted from document reviews, and field notes. All interviews were transcribed verbatim and data organized into e-folders as either audio files, word documents, PDFs, or picture files. E-files were further labeled and organized by date and participant pseudonym. All transcribed data were de-identified, and subsequently uploaded into NVivo 11.0 ®, a qualitative research software for data management. Data were organized and managed in folders created within NVivo and folders were broadly

labeled based on the type of data and the population. For example, interview transcripts from service coordinators were labeled as “Interviews- SC.” Within that folder, interview transcripts for the individuals were stored and labeled with their identified pseudonyms. The same process was replicated for the different populations who participated in the study. Blank forms and general transition documents received from service coordinators, for example, were scanned as PDF files and uploaded into NVivo 11.0 as well. Such documents were also labeled broadly in a separate folder as “Documents-SC.” Pictures taken during tours of some residential settings were also uploaded as JPEG files into NVivo software and broadly labeled under the folder of “community-pic.” Original documents obtained during the study were stored in a locked file cabinet. As earlier mentioned, research records were labeled with a code and a document that linked names, and codes were maintained in a separate and secure location. The documents and audiotapes will be destroyed three years after the close of the study.

### **Data Analysis**

In grounded theory, data analysis is not a linear process, and even though the methods used are presented here as linear, it was applied in a cyclical process throughout the study. Data analysis began after the first interview to facilitate the simultaneous collection, coding, and analysis of data, as is congruent with constructivist grounded theory. In analyzing the data, I employed the use of constant comparative methods consistent with my chosen method. I used the main coding techniques suggested by Charmaz: initial coding and focused coding (Charmaz, 2014).

Coding allowed me to define what was happening in the data and initiated my understanding of the transition process and the meaning attributed to this phenomenon by each participant and as a group within and between the different populations being studied. Codes were constructed and influenced by my interpretation, language choice, my previous experience, and knowledge of the phenomenon of transitions.

### **Initial Coding**

The initial coding was done soon after each interview and usually transcribed before the next interview was scheduled. This coding allowed for theoretical sampling and helped clarify emerging concepts. During initial coding, I assigned a short label (code) to a piece of the data to depict what my interpretation was as to what was happening in the data, consistent with CGT (Charmaz, 2014). Coding was reflective but quick, and it was also spontaneous to avoid forcing data into preconceived codes (Charmaz, 2014). Initial coding allows the researcher to get familiar with the data and help remain attuned to participant views of their realities (Giles, de Lacey, & Muir-Cochrane, 2016). Codes generated were sometimes descriptive, e.g., beautiful and safe setting; others were gerunds depicting process, e.g., sharing information; some codes were also in vivo codes. An in vivo code is a direct word or phrase used by the participant and adapted as code; e.g., in this study different participants used the phrase “checking in” many times during the study. Codes depicting emotions were also generated; e.g., feeling frustrated. As the study progressed, I compared generated initial codes to subsequent interviews. Recoding of initial codes often occurred as a result of the constant comparisons to maintain a higher level of conceptual abstraction congruent with

grounded theory (Giles et al., 2016). Codes that I interpreted as most fitting to the phenomenon of transitioning to the community were explored and developed further as a focused code. For example, the code “it’s all about the person” was developed very early on during the initial coding, and after subsequent coding and comparisons within and across other data collected, it was maintained at a higher level of abstraction to a more focused code. It was later developed as a core category upon which theory was developed. Throughout the process of initial coding, memos were written to reflect my thought process in assigning codes and initial meanings that I was attributing to the codes.

### **Focused Coding**

Transitioning from initial coding to focus coding was not a linear process. It was cyclical and iterative with lots of inductive and deductive reasoning. Focused coding is selective and allows researcher to choose initial codes that have more significance and appear more often (Charmaz, 2014). Selective decision of the researcher was made based on theoretical sensitivity and reflexivity on the phenomenon of transitions, as defined in this study. Focused coding allowed me to synthesize and explain larger segments of the data, which advanced the theoretical direction of the study (Charmaz, 2014). As focused codes were constructed, I searched through interview data looking for incidents where these processes or actions were evident. In instances where these processes or actions were absent, I used theoretical sampling to find participants most likely to explain the phenomenon in subsequent interviews, or I went back to clarify emerging concepts with previously interviewed participants. In such instances, the interview questions were

focused to determine whether these processes or actions could explain participant experiences as suggested in CGT (Charmaz, 2014). Engaging in focus coding allowed me to determine the conceptual strength of the initial codes selected and make a decision as to which initial code should be raised to a higher level of category. Such an identified code became a focus code, and it was then tested against further data using constant comparative method (Giles et al., 2016) and developed as a major category. The development of categories in this study was also achieved through an iterative process of refining major categories, subcategories, and properties; merging categories into larger categories; and finding how categories fit together (Giles et al., 2016). This iterative process proceeded until theoretical saturation was attained and core category emerged. The iterative process involved constant comparative methods, memo writing, theoretical sensitivity and reflexivity, theoretical sampling, and theoretical saturation, as will be discussed further.

### **Theoretical Coding**

As the iterative process continued, codes became more concrete, and central or core categories that accounted for all the other codes and categories formulated emerged from the data. In this study, the initial code “it’s all about the person” became a focused code. Using constant comparisons and comparing concepts within and across participant data, across the data obtained from the different study populations, among and between codes, and within and across the different data types, it became more obvious that all the concepts and categories directly related to the meaning attributed to this one concept. Thus, it transitioned into a theoretical code. The theoretical code was made concrete

through further analysis, using constant comparisons and validation processes such as participant checking and recoding to ensure that the meaning attributed to this code was consistent in explaining the phenomenon of transitioning to the community, as presented within and across data. A substantive grounded theory was developed once the theoretical code was concrete and all its properties and relationships were fully developed, and saturation attained. The theory being proposed from this study that “transition of an individual with TBI from a long-term care facility to community is all about the person,” is depicted in a Model (see Figure 5) and will be elaborated upon in Chapter 5 of this thesis.

### **Constant Comparative Method**

According to Charmaz, the constant comparative method is “a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with code, code with code, code with a category, category with category, and category with a concept.” (Charmaz, 2014, p. 342). Throughout this proposed study, I made comparisons of different people’s beliefs, actions, and experiences; compared data from the same individuals with themselves at different time points during the study; compared incident with incidents; and compared codes with categories and categories with memos (Giles et al., 2016). This method helped to generate theory based on the data and not on preconceived ideas or existing theories. It also helped stimulate my thinking about incidents, constructed concepts, and categories, which in turn enhanced theoretical sensitivity (Jeon, 2004).

### **Theoretical Sensitivity and Reflexivity**

Theoretical sensitivity is a researcher's ability to have insight, understand, and give meaning to the data, and being able to separate what is relevant from what is not (Strauss & Corbin, 1990). Theoretical sensitivity is also attained through some sources, e.g., literature, professional experience, and personal experiences (Strauss & Corbin, 1990). My professional experiences as a nurse facilitating transitions of individuals with TBI, as well as my experiences as an immigrant who has experienced some form of transition, and my prior knowledge of existing literature, gave me insight and ensured my sensitivity to the phenomenon under study. However, despite this rich knowledge base, I was aware that this could potentially make me oblivious and blinded from seeing things that have become routine or "obvious" (Strauss & Corbin, 1990). Therefore, throughout the study, I actively engaged in reflexivity to examine my meaning, actions, and experiences to help minimize bias. Reflexivity was done by engaging in regular discussions with my Ph.D. supervisor, writing reflective and theoretical memos, and keeping a journal.

### **Memo Writing**

Writing of memos is integral to grounded theory. According to Charmaz, memos help increase the level of abstraction of one's ideas and also creates an interactive space for having conversations with self (Charmaz, 2014). In this proposed study, memos were written after each interview to reflect on participant experiences and my experience as a researcher of the interview process. Memos were written to document the thought



processes involved in constructing codes and making decisions for theoretical sampling and further interviews. These memos captured my thoughts on constructing categories and subcategories and finding how they fit. They were also written to help clarify and define emerging concepts. Memo writing always kept me close to the data, as I engaged in constant dialogue with myself throughout this study. This also enhanced the rigor of the study.

### **Theoretical Saturation**

Theoretical saturation occurs in grounded theory when “gathering data about a theoretical category reveals no new properties nor yields any further theoretical insight into the emerging grounded theory” (Charmaz, 2014). In this study, data collection and analysis continued until a core category emerged and theoretical relationships seemed concrete with the data, and I felt no new concepts or properties were developing and saturation had been attained. Once that was established and agreed upon with my advisor, I proceeded to validate my findings by recruiting three (3) new participants: 1) a service coordinator; 2) a family caregiver and; 3) a nurse involved in the transitioning process. These individuals were presented with the developed preliminary theoretical model on transitioning to the community and interviewed. They were asked if the model reflected their experience of transitioning an individual with TBI from a long-term care facility to the community and asked to explain why. Follow-up questioning was done as appropriate, to fully saturate the properties of each major category (Giles et al., 2016). Each of the three (3) participants overwhelmingly felt that the transitioning process was about the person and affirmed the core category of the theory and its properties, often relating them to their own experiences with the transitioning process.

Furthermore, existing transcripts were re-coded against the major categories to ensure no new theoretical insight or meaning lingered (Giles et al., 2016).

### **Thematic Analysis**

In defining successful transitioning and identifying the perceived role of the nurse in the transitioning process, and as part of the aims of this study, a thematic approach to analyzing the data was employed. Thematic analysis is an approach used in extracting meaning and concepts from a data (Javadi & Zarea, 2016). It involves identifying, examining, categorizing, and recording patterns or themes emerging from the data to make meaning of a phenomenon under study. Thematic analysis is a flexible method of analysis, and it fits into a constructivist worldview. Before commencement of the analysis, interview transcripts were checked with audio recordings to ensure the accuracy of content. Data was then coded line by line to attribute meaning to what may

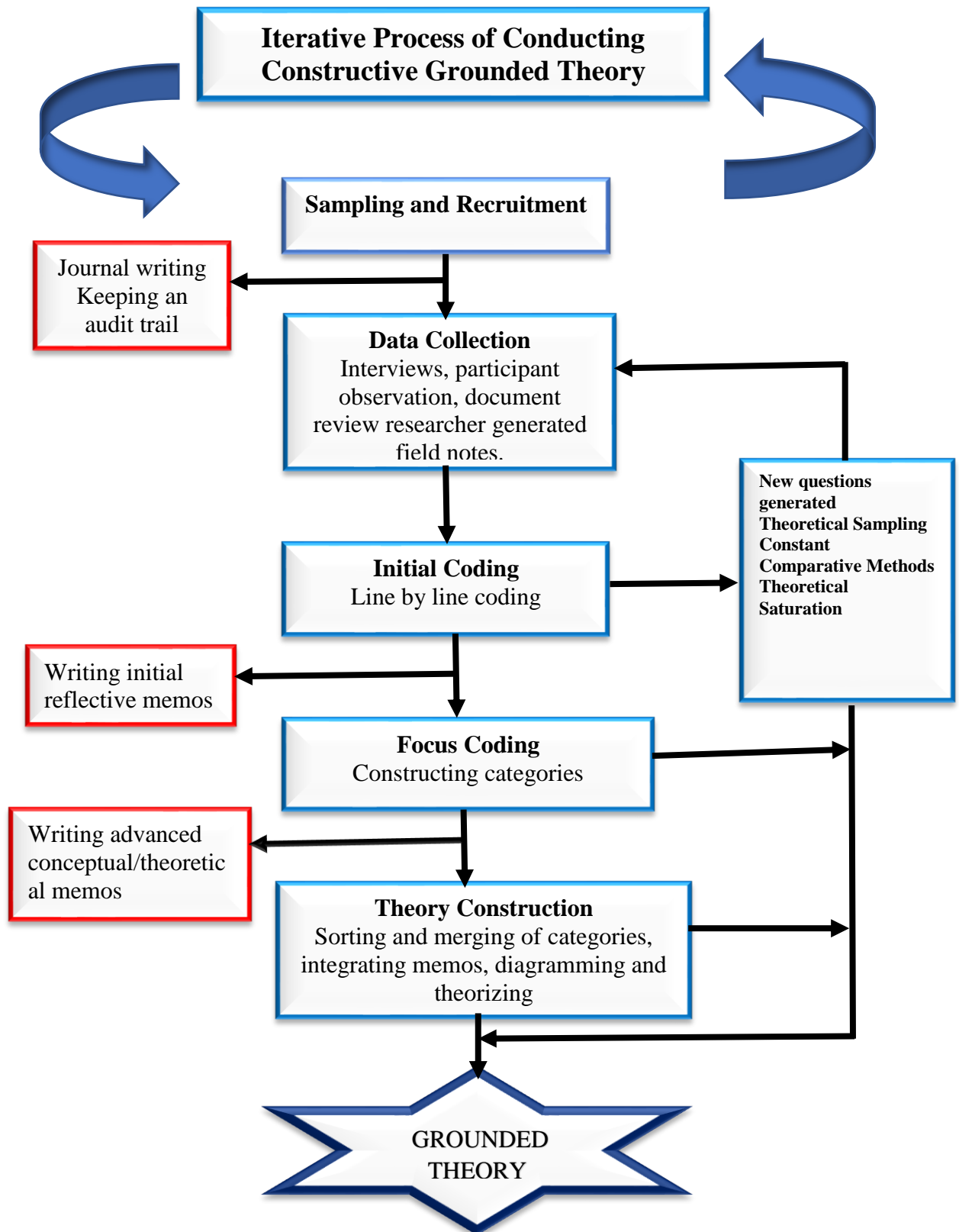


Figure 3: Iterative process of conducting constructive grounded theory

be happening in the data. Initial codes were examined for patterns or related ideas and then categorized into much broader themes or concepts. Categorization of themes continued until the highest level of abstraction was achieved. The proposed definitions with original data were then shared with two participants who had agreed to check and verify study findings.

### **Trustworthiness**

Trustworthiness is establishing credibility, generalizability and transferability, dependability, and confirmability in a study (Cope, 2014). Throughout this study, trustworthiness was maintained as described below.

### **Ensuring Credibility**

Credibility in qualitative research is ensuring that findings of the study are robust, comprehensive and reflective of participants' truth. In this study, credibility was established using reflectivity (as previously described), triangulation, participant checking, and peer debriefing.

### **Triangulation**

Triangulation is the use of multiple methods or data sources in qualitative research to develop a comprehensive understanding of phenomena (Patton, 1999). In this study, triangulation was achieved by collecting data from the individual with TBI, family caregiver, professional caregivers, and community service providers. Furthermore, triangulation in this study was achieved using multiple methods of data collection, including interviews, observation, document review, and researcher generated field notes.

### **Participant Checks**

Participant checks is cross-checking emerging concepts against participants' meaning of the phenomenon being studied to enhance the credibility of the theory developed (Cooney, 2011). Engaging in participant checks allows the researcher to be reflexive and ensure self-awareness and self-correction (Bowen, 2009), while maintaining the delicate balance of theoretical sensitivity. In this study, participant checks were used indirectly through theoretical sampling to develop theoretical categories and directly through re-interviewing of participants to establish emerging categories. As part of this process, three selected participants, including one service coordinator, one family caregiver, and a transition nurse were presented with the model developed and the findings on the transitioning process. They were then asked the questions: "Is this how the process of transitioning process from long-term facility to community is to you? Why or why not?"

### **Peer Debriefing**

Lincoln and Guba (1985) describe peer debriefing as a useful technique for establishing the credibility of a study. They went further to suggest four reasons to engage in peer debriefing and these they asserted were to:

- Keep the inquirer "honest" by probing for meaning, bias, and understanding
- Provide an opportunity to "test working hypotheses that may be emerging in the inquirer's mind."

- Provide an opportunity to develop and test subsequent steps in an emerging design
- Provide "an opportunity for catharsis" (Lincoln & Guba, 1985, p. 308).

During this study, I met with my supervisor regularly to review my codes and themes generated during the analysis, and to engage in in-depth discussions with her about emerging concepts. These regular discussions ensured that I remained faithful to the data. During our dialogues, there were many instances when she would probe to ensure that concepts were reflective of the data. Our discussions often stimulated deep and reflective thinking on my part, which steered me towards the theoretical conceptualization of emerging concepts. Our meetings were often cathartic as well, as the journey was sometimes lonely and stressful, and being able to talk through the difficulties always was a source of emotional relief.

### **Generalizability and Transferability**

Generalizability and transferability were enhanced by following strict procedures consistent with constructivist grounded theory method as described by Charmaz (2006). The concurrent approach used in collecting and analyzing data, using theoretical sampling strategies and methods of analysis such as constant comparison, coding, memo writing, and theoretical saturation, was consistent with said method. Also, an explicit description of the phenomenon under study has been outlined throughout this study. This description was done to conform to the assertion that by explicitly describing a phenomenon, it allows other researchers to be able to evaluate the extent to which study findings may be transferable to other times, settings, situations, and population

(Amankwaa, 2016). Descriptions based on transcripts of interviews from 29 participants (1 individual with TBI, 3 family caregivers, 15 professional caregivers, 10 community service providers), 9 observation notes from individuals with TBI, 28 researchers' generated field notes, 8 individual transition documents reviewed (with total pages of 26), 3 transcripts of reviewed documents, 40 pictures analyzed, and numerous memos are represented in this thesis.

### **Dependability and Confirmability**

To further enhance the elements of trustworthiness, the principles of dependability and confirmability was adhered to in conducting this study. Dependability is the stability of the data over time and the conditions of the study (Polit & Beck, 2014, p. 323). In this study, dependability was achieved by keeping an audit trail.

### **Audit Trail**

Keeping an audit trail involves the systematic recording and presentation of information about the data gathered and the processes involved in conducting a qualitative research study (Bowen, 2009). A well laid out trail of how the research was conducted enhances the rigor of the study, since it allows for reproducibility of the processes involved in constructing theory (Bowen, 2009). Thus, enhancing the trustworthiness of the study. In this study, a reflective journal was kept outlining in detail the stages of the research process and the thought process of the researcher from the start of the study to the end. The researcher used diagrams to outline thought processes throughout the study, as appropriate. Diagramming was also used to show relationships

and links between categories. A trail of how codes were selected and how they emerged into categories /subcategories, and how the core category and theory emerged, was laid out using NVivo ® qualitative software as an audit trail. Hard copies of transcribed interviews, pictures and written drafts, recruitment records, demographic records, research activity log, and interviews were also kept as part of the audit trail.

### **Qualification of the Researcher**

I became a nurse in 2004 and started my career working as a staff nurse at Whittier Rehabilitation Hospital. I worked mostly with individuals with traumatic brain injuries and spinal cord injuries. I later moved on to work at long-term care facilities in different capacities. For the last five years, I have been working as a nurse reviewer with the Department of Disability and Community Services at the University of Massachusetts Medical School in Worcester. My current role is to facilitate the transitioning of individuals with acquired brain injuries and other chronic illnesses or disabilities from long-term care facilities to living in the community using the ABI and MFP Medicaid waiver programs. As a nurse reviewer, I conduct interviews, review medical records and assess for clinical and psychosocial needs and risks, and determine eligibility for a safe transition to the community under the waiver program.

Although I am directly involved in the process of transitioning, my encounter with the process is limited to determining eligibility to the program. The actual process of coordinating and managing transitions from long-term care facilities to community remained mostly unfamiliar to me, since other state agencies are responsible for administering those aspects of the process. Thus, my quest to understand the entire



process of transitioning to the community. My work as a nurse reviewer did help in gaining access to my study population. Also, the skills I acquired with my years of conducting intensive interviews and completing medical record reviews, were helpful in obtaining rich data during this study.

Furthermore, during my doctoral study at the University of Massachusetts Amherst, College of Nursing, I successfully completed my coursework, which included courses in qualitative research and an independent study on grounded theory methods. These courses helped me with designing my study, recruiting my sample, collecting data, and conducting an ethical research study. During my course of study, I successfully conducted and completed a study to define the concept of community integration involving four (4) individuals with TBI and five (5) family caregivers who transitioned back into the community after acute inpatient rehabilitation. In addition to coursework, I read several books and articles related to transitioning. My work on transitions has been presented at national conferences. I have also had the privilege of giving expert testimony to the Massachusetts Senate Financial Services Committee on An Act Relative to Cognitive Rehabilitation S 485/H 843, on behalf of the Brain Injury Association of Massachusetts. I also have a couple manuscripts in preparation to be submitted for publication in peer-reviewed journals. The attached Curriculum Vitae (CV) (see Appendix S) provides detail of my experiences, training, and qualifications.

### Study Timeline

The study lasted for one year and 3 months as outlined in Table 7 and described below. The proposal of this study was successfully defended on February 13th, 2017.

Table 7: Study timeline.

	2017											2018				
	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M
STUDY ACTIVITY	E	A	P	A	U	U	U	E	C	O	E	A	E	A	P	A
	B	R	R	Y	N	L	G	P	T	V	C	N	B	R	R	Y
Defense of Research Proposal	x															
IRB Application and Data Management Planning		x	x													
First IRB Approval					x											
Second IRB application to DDS						x										
Approval from management at DDS							x									
Data Collection							x	x	x	x	x	x				
Data Analysis								x	x	x	x	x	x			
Thesis Write Up													x	x	x	
Defense of Thesis																x

Institutional Review Board (IRB) approval was granted on June 20th, 2017 from the University of Massachusetts Amherst. A Second IRB approval was sought from the Department of Disability Services (DDS) in August. However, a letter was received to indicate such approval was not needed as the study did not involve ID/DD population (Appendix C). Approval to proceed with the study was therefore granted by the management at DDS on August 8th, 2017 and participant recruitment started almost immediately. Recruitment began with service coordinators from DDS on August 31st, 2017. Data collection continued from then until February 2018. Data analysis started in September 2017 and ran concurrently with the data collection process, consistent with

grounded theory methods. Analysis, however, continued until March 2018. Within the period from August 2017 to February 2018, an iterative process of theoretical sampling, memo writing, and data analysis was ongoing, resulting in the development of a preliminary model. Although data collection and analysis continued from January 2018 to May 2018, the focus shifted to dissertation writing. (See Table 7).

### **Summary**

A constructivist grounded theory (CGT) study design was adopted for this research study. This study explored the phenomenon of “transitioning to the community.” Principles specific to constructivist grounded theory was employed consistently throughout this study. Data collection and data analysis occurred concurrently throughout this study. Data were collected using multiple methods to ensure triangulation consistent with CGT. Methods included interviews, observation, and document review. Data were analyzed using thematic analysis and constructivist grounded theory techniques. These included: theoretical sampling, constant comparisons, coding (initial, focus, theoretical) memo writing, theoretical sensitivity, and theoretical saturation, as explained in this chapter.

To ensure trustworthiness of this study, the principles of reflectivity through journaling and memo writing was followed to minimize researcher bias and preconceptions. Credibility was established through member checking with participants to ensure accuracy. I also used peer debriefing strategies and triangulation to further enhance the reliability of this study. Generalizability and transferability were considered in this study by conforming strictly to the procedures of conducting grounded theory, as in the concurrent use of data collection (theoretical sampling) with data analysis (constant

comparisons, coding, theoretical saturation and theoretical sensitivity) in a systematic and iterative process. Dependability and confirmability was also enhanced in conducting this study by keeping an audit trail within NVivo® 11 qualitative software and by outlining a clear description of the research process.

Furthermore, the protection of human subjects was of high priority throughout this study due to the vulnerability of some of the study participants. The standard principles of human protection were followed, as the study was reviewed by two institutional review boards. I went to great lengths to maintain the privacy of all participants by ensuring anonymity and restricting access to all data collected during the study. My participation in the CITI training was influential in helping me stay true to the standard principles of conducting an ethical study.

Lastly, in this chapter, I also outlined my qualifications as a researcher of this study. My experiences in conducting research and working with the TBI population, as well as my in-depth knowledge of the phenomenon under study, was valuable in providing a lens through which data was analyzed and interpreted.

### **Overview of Research Findings**

Findings of this study are reported in six upcoming chapters of this dissertation. Chapter 4 will present findings on the definition of a successful transitioning from the perspective of the individual with TBI, their family caregivers, professional caregivers, and community service providers. Chapter 5 will describe the core phenomenon of “it’s all about the person,” that emerged from this study. Chapter 6 will further describe the key transition processes that the individual with TBI, their family caregivers, professional

caregivers, and community service providers engaged in during the process of transitioning. Chapter 7 will give a detailed description of the process of transitioning from a long-term care facility to a residential group home in the community. The factors that influence the transition process will be discussed in Chapter 8, and ultimately the perceived role of the nurse in this process will be described in Chapter 9. Chapter 10 will provide an empiric-based discussion of all findings reported in this study and draw a conclusion.

## **CHAPTER 4**

### **DEFINING SUCCESSFUL TRANSITIONING TO COMMUNITY**

#### **Introduction**

Defining successful transitioning is key in enabling further research and development in transition studies. In this study, the concept of successful transitioning was explored by interviewing individuals with TBI, their family caregivers, professional care providers, and community-based service providers involved directly with managing transitioning of ITBI from long-term care facilities to residential group homes in the community. Data obtained from participant observations, as well as transcripts from document reviews, were combined and analyzed using a thematic approach. The use of diverse sample and varying sources of data was to capture a combined perspective of how successful transitioning was being perceived and defined by all entities involved in the process of transitioning from long-term care facilities to the community.

#### **Definition of Successful Transitioning**

One individual with TBI, three family caregivers, fifteen professional caregivers, and ten community service providers were interviewed to determine their meaning of successful transitioning in the context of long-term care transitions to the community. A total of three individuals with TBI were observed and their Individual Service Plans and health records reviewed and analyzed, to explore further the meaning of successful transitioning. Data were synthesized and one overarching theme “positive outcomes of

transitions” encompassed the definition of successful transitioning among study participants. Two key themes: positive life changes, and positive process outcomes; and four subthemes: psychological, physical, subjective, and objective were identified. Subthemes comprised of a total of thirteen other themes as depicted in Figure 4 below.

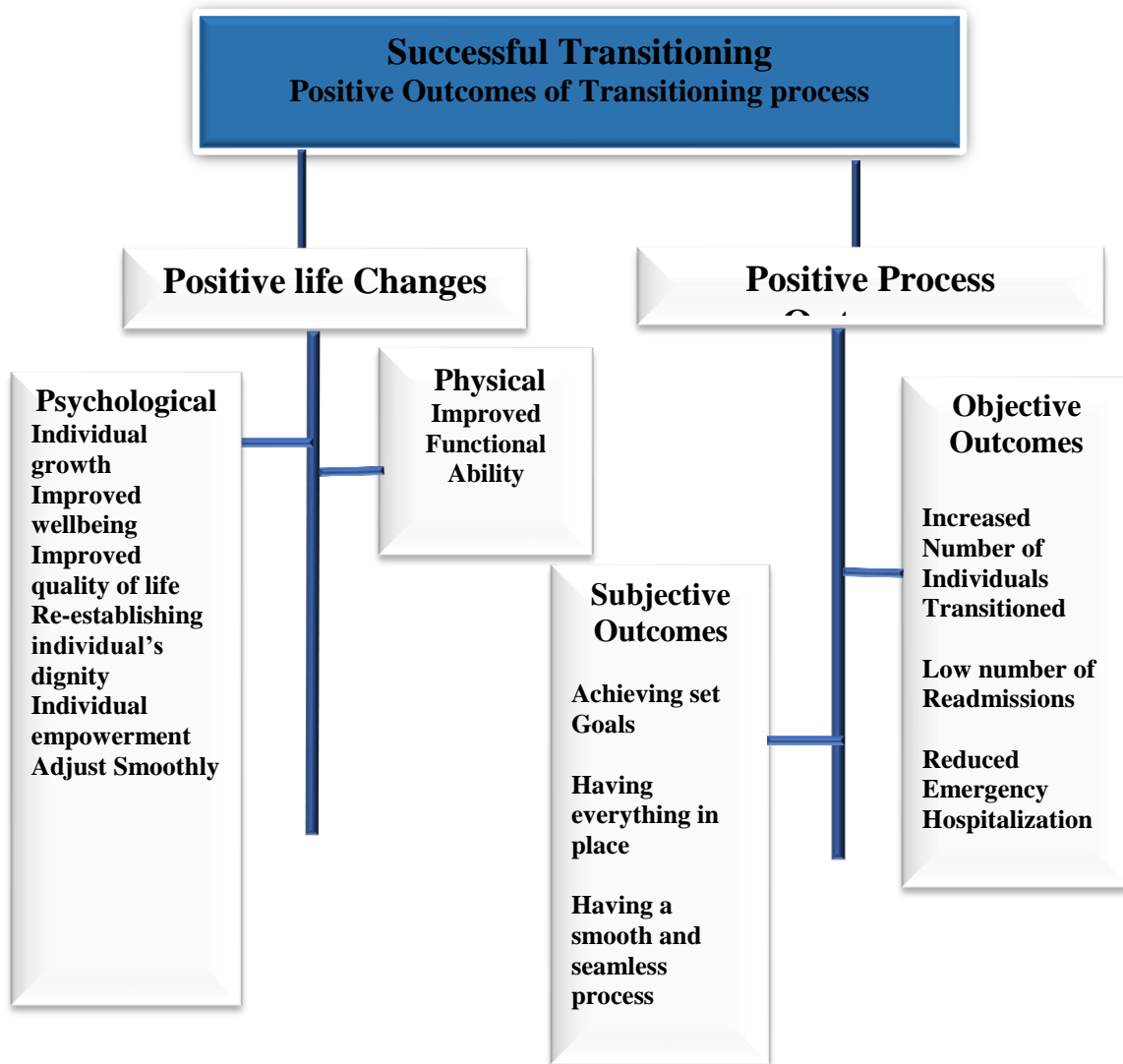


Figure 4: The overarching theme, key themes, subthemes and sub-subthemes.

### **Positive Outcomes of Transitioning Process**

Successful transitioning was perceived by all study participants as positive outcomes resulting from the transitioning process. Such positive outcomes were viewed by some study participants in a procedural context, while others perceived it from a person-centered context. From a person-centered context, successful transitioning was perceived as positive life changes experienced by the individual as a result of his/her transitioning from the long-term care facility to the community. From a procedural context, participants viewed success as achieving positive process outcomes. The synthesized themes that make up the broad definitions of positive life changes and positive process outcomes will be discussed further.

### **Positive Life Changes**

Participants in this study perceived success as the positive psychological and physical changes that had occurred in the individual's life following his/her transition from the long-term care facility to live in a residential group home in the community. A thorough description of such life changes are presented as follows.

### **Positive Psychological Changes**

Positive psychological life changes were perceived as desirable personality (emotional and mental) changes noted in the individual with TBI as a result of their transitioning from the long-term care facility to the community. The psychological changes described by study participants included: positive individual growth, improved



wellbeing, improved quality of life, re-establishment of individual's dignity, individual empowerment and adjusting smoothly.

### **Positive Individual Growth.**

Growth has direction and always implies a value of judgment, and it is often judged by the sense made of the past (Irving & Williams, 1999). According to Zoellner & Maercker (2016), personal growth is an experience of psychological development as compared with a previous level of functioning or previous attitudes towards life (Zoellner & Maercker, 2006). An individual is perceived as having achieved growth when he/she becomes more capable and competent, more productive and creative, more insightful and understanding, more knowledgeable, prudent and discerning (Arkoff, 1975).

In this study, participants described successful transition as positive personal growth for the individual with TBI. They associated growth with their ability to become more capable and competent in their functioning such as mobility. One DDS service coordinator explained positive individual growth this way:

“From what I've seen, a successful transition is you know when you follow that person from the beginning up until the time that they move on to the community and then you see that they've just grown. And you see that are they've-- there's an individual that is hmm living in a home, who when she was in the nursing facility, she was in the wheelchair all the time. She's at the point now where she is pretty much always walking. Which is amazing!” (Sue Smith- Service Coordinator)

The extent of growth these individuals with TBI attained after they transitioned out of the long-term care facilities was often drastic and transformational. One professional caregiver described the transformations he perceived as surreal and short of a miracle. He perceived the individual with TBI as becoming more capable in her mobility, more

insightful and knowledgeable, and able to hold a meaningful conversation which she could not do in the past.

“It’s just watching the drastic improvement of these individuals who their life has been snapped away in an instant..... we’re talking about people like you or me, driving down the street and getting hit in a car accident or riding their bike. Ahmm and you know or fall in a grocery store or shoveling their driveway and slipping on ice. Simple stuff like that impacting their lives to the point where .... not recognizing their family.... Now to the point where they are getting the services they need, the independence, the growth Ahh the positive reinforcement. The processes along the way and then seeing ...thinking of this woman again to the point where she’s walking in a walker, making strides.... basically, she was told she was a quad and will never have those things again. She remembers who her kids are now.... to the point where she can have a full conversation with you now, and her sassy attitude comes up when she talks with you. This is a woman who couldn’t talk when we took her out...” (Chip, DDS Service Coordinator)

### **Improved Wellbeing.**

Improved wellbeing was a desirable psychological change perceived, and/or experienced by study participants as successful transitioning. Wellbeing in this study is defined as a combined state of being happy, maintaining a healthy life or being comfortable.

**Being Happy.** Being happy was a common emotional expression used by participants during this study to portray a sense of contentment and as evidence of having attained a successful transitioning. One service coordinator describes a situation where the individual with TBI was showing improved wellbeing as he was happy and was without pain.

“That for me is success, that he is happy, not the gratitude, just that he is happy, he is without pain, there is a light at the end of the tunnel and he starting to see it, that’s success!” (Jessica, DDS Service Coordinator).

Dave was observed as thriving in the community. He often was jovial, and he engaged socially with staff at the group home. He indicated how happy he was to have moved out of the long-term care facility into the group home.

“I am so happy to stay here.” (Dave, Individual with TBI)

A similar sentiment was shared by one family caregiver who indicated that transitioning had been successful as his father was very happy in being in the group home.

“My...this is the best transition my dad has ever had he is happier here than he has been anywhere else. So, that's success to me, is to see my dad not complaining every day and begging me to come get him or whatever, so that's a huge, huge difference.” (Chossey, Family Caregiver)

**Maintaining a Stable Healthy.** Maintaining a stable health after transitioning from the long-term care facility to the community was perceived by study participants as having enhanced the wellbeing of the individual with TBI. In that, the individual with TBI's has stayed out of the emergency room, has had no serious illness and has had a continuity of care since their transition to the community.

“All the time that I have discharged someone to one of those UMass waiver houses, it's been successful in the sense that they didn't go to the emergency room. They didn't have any serious illness or hiccup out in the community; staff is keeping them in line in the sense of continuity to follow their medication, making sure that they were doing their daily routines and sticking to that schedule.” (Nicole, Facility Social Worker)

Maintaining such stability and staying out of the long-term care facility was defined by other study participants as a successful transitioning to the community and a perceived enhancement in their wellbeing.

“A successful transition, as a service coordinator...They're at stable baseline medically.” (Jessica, DDS Service Coordinator)

“A successful transition means that they can get out, stay out and be safe and healthy in the community. Ummm That they’re happy and healthy. Really! I mean that’s success.” (Ava, Facility Social Worker)

However, maintaining a stable health and attaining a successful transition was noted to be sometimes difficult, though it could be achieved with some perseverance. A professional caregiver expressed how difficult this was for one of her clients.

“I’ve had a couple of people do that (maintain a stable health), but it has taken a lot of medical bumps in the road to get them to that point sort of about eight months out, six months out now and he’s...this person is finally to a point where he’s like, I’m not in as much pain anymore...., I feel so much better now thank you so much for putting me here, helping me get here.” (Jessica, DDS Service Coordinator)

**Living a Comfortable Life.** Participants also expressed contentment with living a comfortable life after transitioning to the community; comfort was sometimes described as being in a beautiful home-like setting. Such contentment or perceived wellbeing was described positively as an outcome of the transition process and indicated success.

“you know, going from one place to another place but knowing that he was going into more of a house setting-- a home setting, I think that was easier for him, emotionally because it was more homie.” (Glinda, Family Caregiver)

“I’ve...yeah I used to do VNA work too. So, I’ve-I’ve been in the homes, and I got to see what they look like and-and how people interact there and how comfortable they are and its-it’s awesome-it’s awesome!” (Rickie, Facility Social Worker)

“The house was just so gorgeous. I was like I want to live here, look at this kitchen. So, he was excited about it,” (Nicole, Facility Social Worker)

In simply living and enjoying their lives after transitioning out of the long-term care facility to the community, individuals with TBI showed contentment and improved wellbeing, which was positive to their transitioning experience and therefore successful.

“And so, when you see somebody who never thought they could walk again. Walking and then getting a job and you go to visit them, and every time you see

them, they're just happy. And they're just really enjoying life and going go into the community and doing things that they enjoy.” (Sue Smith, DDS Service Coordinator)

### **Improved Quality of Life.**

A successful transition was defined in this study as a positive change in the quality of life experienced by individuals with TBI because of their transition out of the long-term care facility to the community. Quality of life was perceived as having a healthier lifestyle, participating and engaging socially in the community and being less medicated.

“But just listening to her talk about the progress of some of the ladies and the improvements that....and the quality of lives that they have, they do everything .... just watching them and how well they are still doing and continue to do, is wonderful.... she is doing more walking.... She’s lost weight, in a healthy way, she’s watching her diet, following what the doctors are saying. Just ---she was way over medicated in the nursing facility so the psychiatrist that they used through the agency, started to take her off some of the meds and the clarity that she now has and the engagement that she has and the effect she has is just so much more normal than what she had before.... It’s amazing, amazing.” (Antonia, DDS Service Coordinator)

“....one of them she started to go to day program now, eventually. So... it’s a success story; the family is very happy, the quality of life improved compared to how it was at the nursing home.... they go to outings go to the movies and stuff like that. They’re doing a lot of work there and really improve the quality of life.” (Ubda, DDS, Service Coordinator)

“I mean that’s what it comes down to, the quality of life improves dramatically when they are out these SNFs...” (Chip, DDS Service Coordinator)

### **Re-establishing Individuals’ Dignity**

Dignity in this study is as defined by Jacelon et al. (2004), “Dignity is an inherent characteristic of being human, it can be subjectively felt as an attribute of the self and is

made manifest through behavior that demonstrates respect for self and others” (Jacelon, Connelly, Brown, Proulx, & Vo, 2004). A successful transition in this study also meant re-establishing an individual’s dignity during their transitioning from long-term care facility to the community.

“.... I had a twenty-seven-year-old girl who lived in a nursing facility in Worcester and again... so, twenty-seven she was in a car accident, and she was allowed to shower once a week, you know, so this... we're talking about somebody's dignity here, you know, a 27-year-old girl who was in hairdressing school took a lot of pride in her appearance, and everything was able to shower once a week.... she had this long beautiful curly hair, and by the time she left, it was up to her ears because they've kept coming and cutting her hair ...She was able to move out, when she moved she had a feeding tube, she was in pull-ups and through just rehab in the community and more ...interaction with people her own age, she doesn't have a feeding tube anymore she is just wearing regular underwear--- But that's, I feel like what's, what is really beneficial and is meaningful” (Sue White, DDS Service Coordinator).

### **Individual’s Empowerment**

Empowerment, as defined, is the individual’s ability to manage challenges and overcome the sense of powerlessness (Wåhlin, 2017). In transitioning individuals out of long-term care facilities, professional caregivers felt that individuals had been empowered as they had overcome their sense of powerlessness and had been given their voice to choose and make decisions in their own lives. This was a positive life change for them and was perceived as successful transitioning.

“Because if nothing else, it has given somebody who has been institutionalized a voice and it's been giving somebody who was institutionalized a choice and a decision into their own lives versus this is when you're going to eat, this is when you're going to get up, this is when you're going to get dressed, this is when you're going to go to a day program. So just allowing somebody to have a voice and a choice and listening to that I think is a huge success.” (Elizabeth Hapgood, Rehabilitation Director).

“I feel it is...giving people empowerment and voices and things of that sort...to have people who are...who've been cared for, for so long that they have lost that

ability to think and function for them self ... I think it's a beautiful thing when I start working with a person like that in the beginning and by the time we're like a year in, this person is like speaking up. They're telling staff what they want; they're not asking anymore; they now embrace that voice that you have.... I find it an amazing thing to see a person actually gain a voice.” (Tina Marie, DDS Service Coordinator)

Being empowered gave them a sense of freedom or liberation, since they could decide for themselves and determine, for example, when to go out.

“So, it has been a successful transition for him because his families got to see him, and he gets to go out into the community when he wants.” (Caitlyn, Residential Program Director)

One individual with TBI, for example, felt liberated from not having to use a wanderguard device on his wheelchair so he could be free to get around as he pleased. Something he could not do in the long-term care facility.

“The last place I was, I had security on my wheelchair, I like it here....my freedom!” (Chaos, Individual with TBI).

### **Adjust Smoothly**

Adjustment is the process of modifying one's behavior in changed circumstances or an altered environment to fulfill psychological, physiological, and social needs (Townsend & Morgan., 2018). Being able to adjust well to the new environment was also considered by the staff as successful transitioning.

“Being able to adjust smoothly. There is always going to be some sort of hiccup along the line anyway...” (Joe Smith, Residential Program Director)

“Well, I think that once that----if the resident adjusted fairly easily and was able to maintain stability, you know, because they have the supports that are needed. To me, that would be successful.” (Rose Quartz, Facility Social Worker)

Adjusting well to the new environment included getting used to the other individuals residing in the residential group home setting by making new friends, participating in

social activities at the home, and the community. It also meant getting used to and accustomed to their new medical providers in the community.

“So, it has been a successful transition for him because.... He gets to enjoy his time, he’s made a great companion and a friend and our other individual that lives here, they smoke together, they talk about the past. So, there's a lot of different aspects of it.” (Caitlyn, Residential Program Director)

### **Positive Physical Changes**

The positive physical changes and the psychological changes individuals experienced during transitioning occurred simultaneously. The positive physical life changes experienced often manifested as improvement in the functional ability of the individual who transitioned out of the long-term care facility to the community.

#### **Improved Functional Ability**

These positive physical changes included improvement in their ability to participate in some activities of daily living (ADLs), such as eating. They also showed improvement in functional mobility, which was often perceived by the professional caregivers as successful transitioning.

“She couldn’t hold her head up and couldn’t feed herself; now she’ll sit at the dinner table with silverware and cut it and feed herself. It’s just the strides, and we’re talking, a year and a half out of the SNF, that this happens so Ahmm, yeah. If there someone that you want to include in this situation who is such poster child TBI.... unbelievable strides.” (Chip, DDS Service Coordinator)

“.....There are several you know, who have come out of the facility and at one point were not walking, and now they’re walking, because they’re getting PT three, four, five times a week, compared to getting PT once every two weeks, you know what I mean? And just more or nothing and just more engaged and have progressed to the point that it’s like wow, it’s amazing.” (Redsox, DDS Service Coordinator)



## **Positive Process Outcomes**

Participants in this study also defined success as positive outcomes directly associated with the process of managing transitions out of long-term care facilities to the community. These positive process outcomes were described both subjectively and objectively by participants.

### **Subjective Positive Process Outcomes**

These were positive process outcomes that participants described based on their personal set measures of success during transitioning. Their described measures included: achieving set goals, having everything in place, and having a smooth and seamless process. These measures were most often referenced by the professional caregivers and family caregivers as an indication that transitioning of the individual had been successful.

### **Achieving Set Goals**

Individuals explicitly and implicitly indicated that successful transition was about achieving some set goal(s). The set goals varied, however, and in some instances were vague. The set goals could be achieving whatever was promised to the participant and family before the transition. This was indicated in an interview with a family caregiver, who for the most part expressed deep frustrations about the transition process. This was my attempt as a researcher to explore further what her meaning of successful transitioning was.

**Sylvia:** “What would you consider a successful transition?”

**Mary:** “Well, what they said they were gonna do.”

**Sylvia:** “And what was that? I just want to know.”

**Mary:** “That they were gonna take care of him. That he was gonna have this, this, this, you know, one on one. I mean they would give him food and nobody would sit with him.”

The set goals for some professional caregivers coordinating the transition process was to move them out of the long-term care facility. For them, once that was achieved, the transition was considered successful.

“So, we really, really at the end of the day, we really want to see that person be successful and we really want to see that person move into the community. That's what we want. So, we try everything we can....” (Sue Smith, DDS Service Coordinator)

“Yeah, I mean we all have the same goal, which is to get these people out of the SNFs.” (Chip, DDS Service Coordinator)

### **Having Everything in Place**

In coordinating the transition process, professional caregivers mostly indicated that successful transitioning was having everything in place, such as: durable medical equipment, medications, furniture, and ensuring that primary care physician appointments and specialist appointments are scheduled. Also mentioned was that referrals to day programs or other programs were in place to meet participants needs, as well as the safety or continuity of care as they transition to the community.

“A successful transition, as a service coordinator, would be that they've gotten, they moved all their pieces and parts and paraphernalia have gone with them.” (Jessica, DDS Service Coordinator)

“All equipment has been ordered; all equipment has been delivered. All furniture has been ordered; all furniture has been delivered. PCP appointment has been scheduled, two weeks from the discharge date...So that is what is successful for me.” (Redsox, DDS Service Coordinator)

“What a successful transition is for me, is that at the end of the day the person is moved in, they have anything.....everything they need. The bed got there on time; the fire drill got ran on time. ... they have their, linen their towels, their toiletries. You know, they’re settled in, and you know, they... we know that it’s going to be a successful first night there...” (Antonia, DDS Service Coordinator)

### **Having a Smooth and Seamless Process**

Having a smooth and seamless process was considered a positive process outcome by family caregivers and professional caregivers. Having a smooth and seamless process often came with effective coordination and communication through teamwork, where everyone on the team was on the same page.

“So, a successful transition is, everybody, is always on the same page.”  
(Cassandra, DDS Service Coordinator)

“Yeah! The successful transition is relative...So, for it to be successful, is to have all those things to come kind of together and to have that teamwork go smooth, usually most of the time...” (Ubda, DDS Service Coordinator)

Successful transitions also involved the effective coordination of services through referrals to meet the goals and needs of individuals as they transitioned from the long-term care facility to the community.

“And so, you know, a successful transition would mean that things on that list are getting done. And basically, for that to happen, you know, everyone has a role, everyone has the things they got to do, whether it’s coordinating therapies or scheduling and finding a PCP, finding a moving company if needed. You know, as long as everyone is doing what they need to do, that you know is successful.”  
(Rudy, DDS Service Coordinator).

“...and also meet the needs of the individuals. And if you know—just the organization; the provider if they are well equipped and ready to have this, most of the time we have a smooth and successful transition that way.” (Ubda, DDS Service Coordinator)

One family caregiver indicated a seamless process where everything rolled together causing very little anxiety for the individual with TBI.

“I guess I would describe it being successful just based on his ---/Ahmm how easy it was for him and how .... it was done with the least amount of anxiety for him. You know, and it was like, oh yeah, you're going to your new place, and you know, everything was just done, so that he wouldn't be taken from here and plunked somewhere else.... I mean everything was just kind of rolled together...”  
(Glinda, Family Caregiver)

Another family caregiver indicated a smooth process, with her doing very minimal. Her minimum contribution was because most things were taken care of by the transition staff and all she needed to do was give her approval. She felt the process was “really good,” yet it involved time.

“I did minimal what I should do, you know, and I just had to approve and stuff, but they were really good about transitioning him into the places. Yeah, so it really went...it went as smooth...and it takes time to get the paperwork...”  
(Mary, Family Caregiver)

### **Objective Positive Process Outcomes**

These were positive and measurable outcomes associated directly with the general transition process. These were outcomes participants described based on objective facts outside of their personal views or bias. Such outcomes included, increased numbers of individuals transitioned, low number of readmissions, and decreased emergency room visits.

#### **Increased Numbers of Individuals Transitioned**

Staff from North East Independent Living Inc., a community service provider responsible for helping individuals transition from long-term care facilities to the community, defined success as an increase in the total number of individuals they

transitioned to the community within the last three years of the MFP waivers. They also reported a low number of readmissions among individuals they have transitioned.

“.... What was so amazing about the MFP program is that prior to, ahmm, we would transition probably around like seven to ten individuals a year like without any resources. Like Luz would be trying to, you know, find whatever she could to get these people out and now when we had the funding to support it through the waiver and CMS we would transition over 30, 35 individuals a year....and with like one.... we transition over 110 individuals in three years, and we've had like two readmissions, that's it.” (Kennedy, Transition Coordinator)

### **Reduced Number of Emergency Hospitalization**

A reduction in the number of emergency hospitalizations was also used to define a successful transition to the community. According to one professional caregiver, the significant decrease in emergency hospitalizations was a positive outcome of the transition process.

“At the beginning, we had a lot of emergencies, hospitalization six months later, we cut down the number and if you go and see how--- They just look good! there is a lot of improvement.” (Ubda, DDS Service Coordinator)

### **Summary**

Transitioning processes are costly, and its success is a priority for the state and other stakeholders involved in the process. Therefore, providing a better understanding of what successful transitioning means could give some insight into measuring program outcomes and allotting resources to further enhance the lives of individuals undergoing transition.

In this study, successful transitioning was identified as positive outcomes resulting from the transitioning of individuals from long-term care facilities to the

community. These positive outcomes were either person-centered or process-centered. Person-centered outcomes focused mainly on psychological markers such as personal growth, improved wellbeing, improved quality of life, dignity, individual's empowerment, and psychosocial adjustment. These psychological experiences often were manifested physically as improvement in the functional ability of the individual involved transitioned. As positive process-centered outcomes, the definition of successful transitioning was either expressed subjectively or objectively. Subjectively, success depended on the participants' metrics, such as achieving set goals, and having everything in place, having a smooth and seamless process. Objectively, success was defined using factual data devoid of personal set matrices (increased number of individuals transitioned, low number of readmissions, reduced emergency hospitalizations). The proposed definitions of successful transitioning presented in this chapter are crucial in developing new and accurate measures of transition outcomes that encompasses the meaning individuals with TBI, family caregivers, professional caregivers, and community service providers attribute to a successful transition from a long-term care facility to the community.

## **CHAPTER 5**

### **IT'S ALL ABOUT THE PERSON**

#### **Introduction**

Transitioning is defined as the process of movement of an individual from one location to another such as from a long-term care facility to a residential group home setting in the community. In this study, the process of successfully transitioning individuals with TBI from an institutional setting, i.e., long-term care facility to the community is centered on the individual/person who drives forward his/her transition with community-based supports and services coordinated by a collaborative team including nursing.

This chapter will give an overview of the “it’s all about the person” model of transitioning and will describe the core phenomenon “it’s all about the person” in the broader context of transitioning from long-term care facility to residential group home settings in the community. The concepts to be described under this phenomenon by study participants include choices, human rights, safety, needs, goals, emotional sentiments, wellbeing, and quality of life.

#### **It’s all About the Person Model of Transitioning to Community (IPMTC)**

Transitioning from a long-term care facility to the community is all about the person (see Figure 5). The person is central to all processes that the individual, family caregivers, professional caregivers, and community service providers engage in during their transitions from long-term care facilities to the community. These processes include coordination, communication, team collaboration, planning, checking in, relationship-

building, and social engagement which, in this model, occurs within phases and across the entire transition continuum.

The continuum consists of three phases which occurs over time. 1) the preparation to move phase/pre-transition; 2) the move to community phase/transition phase; and 3) the living life in the community phase/post-transition phase.

The first phase “preparing to move to the community” is a preparatory phase made up of three distinct processes: checking-in process, planning process, and the meet and greet process. This phase is centered on knowing the individual through relationship building, information gathering, and sharing through communication. Planning and coordination of services and supports involving a collaborative team also begin at this phase of the process. All processes at phase one carry through to the other phases.

The second phase “move to community phase” is a transition phase involving the physical movement of the individual from the nursing facility to the community, and focuses on creating and maintaining a safe and welcoming environment by fostering relationship building. During this phase, the individual with TBI goes through a period of initial adjustment. The transition from this phase to the living in community phase is not as distinct, as the time of adjustment depends on the individual involved.

The third and final phase of the continuum is “living in the community phase,” also referred to as the post-transition phase. This phase is focused on fostering the normal aspects of life for the individual with TBI, and it entails maintaining health, socialization (social interactions, social engagement), work, and spirituality. These elements occur amidst community resources and community-based supports.



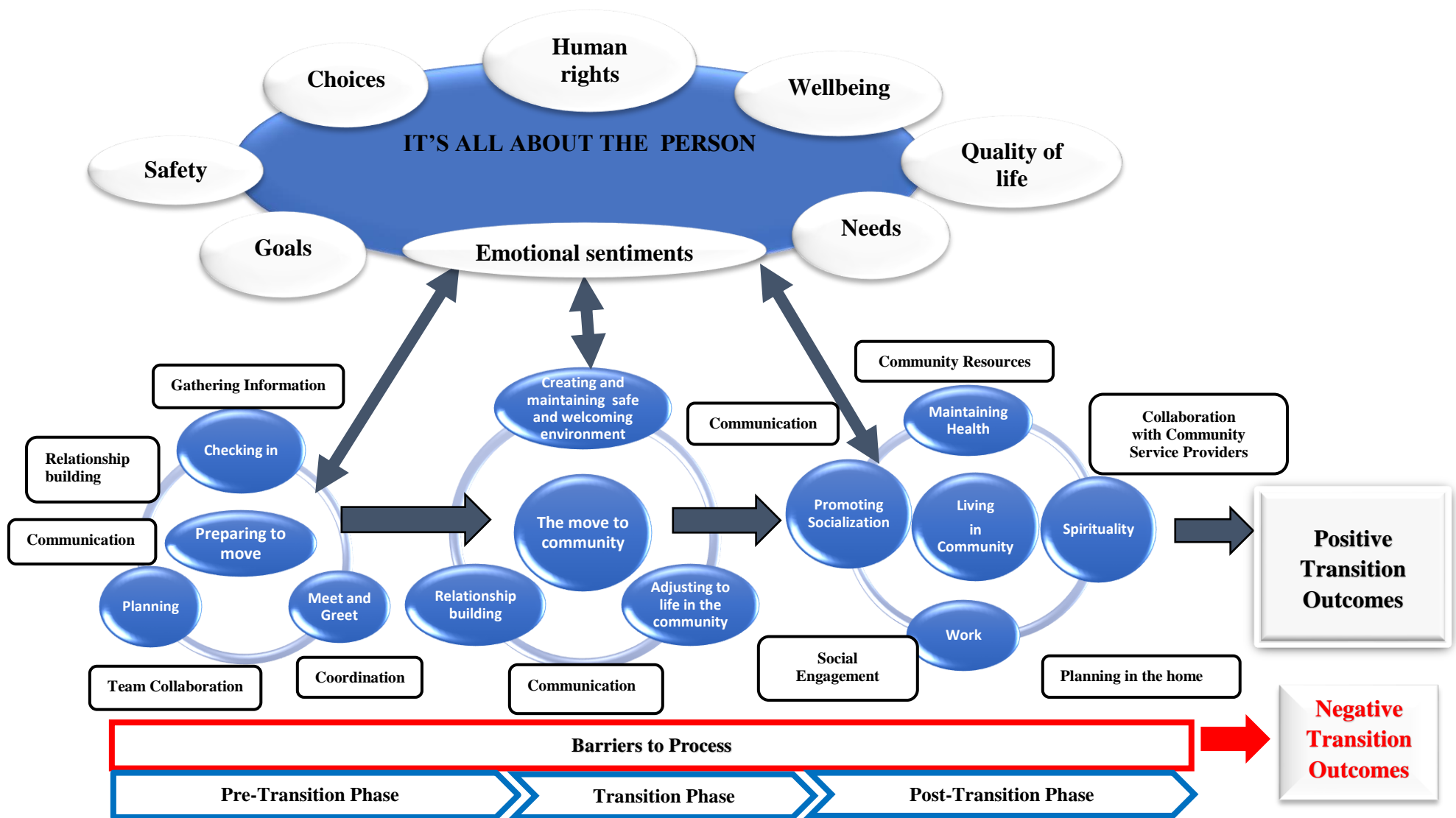


Figure 5: It's all about the person model of transitioning to the community.

The effective management of the transition processes along this continuum leads to positive or successful transition outcomes. Along the continuum, barriers are encountered that, in turn, may lead to negative or suboptimal outcomes (see Chapter 8). The phases of this process will be described further in Chapter 7. A detailed description of the core phenomenon “it's all about the person” in transitioning to the community follows.

### **The Core Category-It's All About the Person**

A person in this model is a bio-psychosocial being with choices, human rights, personal goals, needs, and emotional sentiments who maintains a stable health and builds relationships through interactions with others and social engagement, in the context of community-based supports and services, and whose safety, dignity, well-being, and quality of life is enhanced during the process of transition.

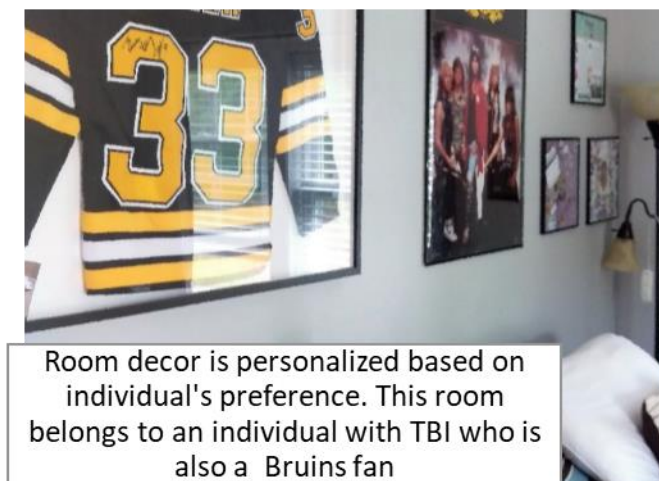
### **Choice**

During the transition process, the choice of the individual is respected and encouraged by professional caregivers, community service providers, and the family caregivers/guardian. According to Williams (1998), “An individual experiences choice when they select one option from similarly attractive but indeterminate options” (Williams, 1998 p.1). The concept of choice often has ethical implications and is associated with one's autonomy and freedom (Zolkefli, 2017). In managing the transitioning of the individual with TBI from a long-term care facility to the community,

the family, professional caregivers, and community service providers always inquired about the individual's choice. They incorporated the individual's preferences in their decision making during the planning process and in the development and implementation of their plan of care. While living in the home, respecting the individual's choice was central to fostering the normal aspects of their lives. Study participants described many instances where the preference of the person or legal guardian was at the forefront during the transition process.

“Well, I got the letter saying he was approved and then it was a matter of speaking with people about where we wanted him to go.... And they were doing everything, you know, that he wanted. Even though we were-we were all a part of it, I was a part of it too, but it was so much more based on what he wanted not what I wanted for him....” (Glinda, Family Caregiver)

“So, we do the evaluation, try to determine the best way to go with the person, and a lot of it just depends on them; what they wanna do. ...So, I always take my cue from the client and try to do whatever they feel is important to them.” .... (Dee, Occupational Therapist)



Room decor is personalized based on individual's preference. This room belongs to an individual with TBI who is also a Bruins fan

Figure 6: A personalized room depicting choice of individual with TBI.

“.... simple as putting on a schedule that Fridays is ...John’s night to pick something, it’s on my schedule then John has that spontaneous choice of what he wants to do on Friday night... we let them make the choices. So, we really, ahmm, promoted individual choice too....” (Caitlyn, Residential Program Director)

“So, it’s up to the individual, as to whether or not they want to attend the day program? You know, if they want to stay at home all day every day, it’s up to them.” (Rudy, DDS Service Coordinator)

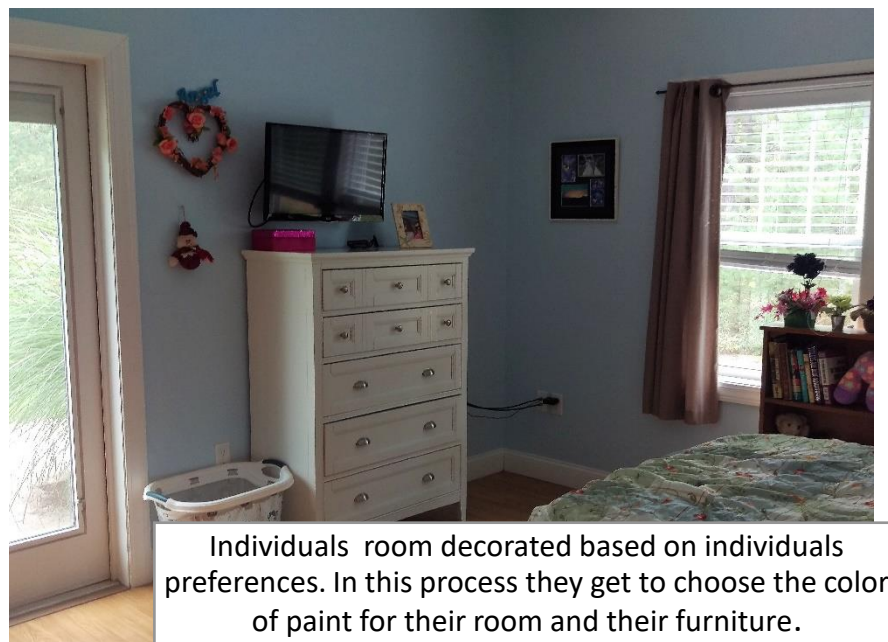


Figure 7: Room for individual with TBI.

## Human Rights

Based on the Universal Declaration of Human Rights from the United Nations in 1948, Rosenzweig emphasized that human rights are: the civil and political rights (e.g., the right to life, liberty, and security of person; the right to freedom of opinion and expression, and the right not to be subjected to torture, or to cruel, inhuman or degrading treatment, or punishment); and economic, social, and cultural rights (e.g., the right to

work and to free choice of employment, the right to education, and the right to participate freely in the cultural life of the community (Rosenzweig, 1988). These rights have since been extended to specifically give individuals with disabilities equal opportunity to exercise these rights under the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations 1993) and cited by (Verdugo, Navas, Gómez, & Schalock, 2012). In transitioning individuals with TBI, their rights as humans and as persons with disabilities are central in the decision making, planning, and service provisions. They are afforded safe and handicapped accessible housing, and their rights to choice, freedom, and autonomy are respected.

“We’ve had consumers tell us I can’t wait to get to my new apartment I’m going to have a big party, and this is a person that’s got a ...you know, an alcohol history or drug history. It’s kind of scary, but again it’s not our role to say no, we can’t work with you because we fear that you’re going to fail in the community. Our philosophy is everyone has the right to fail.” (Summer, Transition Coordinator)

“.... they were like, just so you know that we’re going to let him make decisions for himself... because human rights are important here it’s one of our main focuses...” (Chossey, Family Caregiver)

“Just. you know.... I mean, the human right, the human rights part.... It’s important for us to understand that these people had a life before, they are not minors, we cannot treat them as minors, we need to respect them, all right.... we need to respect their wishes, you know. If somebody tells me, I’m over 21. I’m going to get a Budweiser. I need to respect that, whether I agree with you or not...we need to respect that.” (Redsox, DDS Service Coordinator)

Living in a group setting sometimes presents challenges when adhering strictly to the protection of a person’s human rights. This is because one’s human right may infringe upon the freedoms and rights of others, which sometimes led to conflict.

“So, I said, you know...and they’re like, it’s a human right thing, we can’t take his power chair away from him, and I was like you absolutely can for the safety of your staff and the safety of my father, and he’s competent.... So, I called the police, and the police came around.... I was like I’m seriously going to press charges, like take it to court. I’ll have his competency taken from him if you keep

it up because you're not doing enough to protect my father.” (Chossey, Family Caregiver)

Their rights to participate freely in social activities in the community was also a priority, and it was encouraged throughout the transitioning process.

“So social things are first. We consider their interests first, the positive ones, not the bad areas like to start drinking (laughs) but positive areas like going to movies...this lady wanted to play; she played instruments, she says she wants to play some music and stuff like that. So, we say okay we try to get a keyboard at home, and she can pick up a few classes in the community.” (Ubda, DDS Service Coordinator)

Interestingly, one community-based service provider had personnel/staff, whose role was to ensure that the human rights of the residents were respected.

“One of my individuals who is a **human rights officer**, she'll do the weekly house meetings, and she'll ask them what do you guys wanna do this week do you need haircuts this week do we need to go shopping for Christmas presents? Ahmm and then we'll make it happen.... So, if Carl...and Jay is like yeah, we really want veal this week you know, veal parmesan, love veal parmesan so then we put on our grocery list.” (Caitlyn, Residential Program Director)

### **Personal Goals**

Personal goals are an individual's cognitive representation of his personal motivations (Markus, 1983). Study participants described a process where the goals of the individual transitioning were a central focus. Having personal goals was essential to all three phases of the process. Service coordinators and community service providers helped them to identify and set goals. They incorporated these goals into their planning processes so that the right services would be put in place to help the individual meet their goals and be successful in the community.

“Yes, it's looking at their goals and what they wanna do, but it's also trying to figure out with the staff how they can be more, ahmm, how they can be safer,

yeah, yes you look at the person, the whole person and what you know what they wanna do. What's important to them that's kind of..." (Alyssa, Facility Social Worker)

".... Whether it's getting a job or to drive again or fly a plane ahmm some of them have realistic goals that they want to do and if they don't, we still add it to the vision statement. Because we can get creative with supporting that vision and giving them still the experience to be able to achieve that goal in a way."  
(Cassandra, DDS Service Coordinator)

"What does this person want? What do they feel is best? And that's the goal, and that's what we aim to achieve." (Summer, Transition Coordinator)

"Where do you see yourself? What is your goal here...?" (Luz Marie, Transition Coordinator)

The individual's personal goals are initially set during the preparation phase of transitions and revisited every three months and a year out in an annual Individual Service Plan (ISP) meeting. This process of reassessing goals was necessary because the goals of the individual with TBI evolved and became clearer and more realistic with time.

".... It happens every three months and at the yearly meeting. So.... from the date that they moved in a year later, we're going to have the same meeting, you know, we're going to look back and reflect upon what's happened across the year. Was this a bad goal? Should we kind of get rid of it? And now that you've lived in the community for a year, what do you think you want to do? Because sometimes after three months you don't have a good grasp on it, you just kind of have pipe dreams.... It took one woman that I worked with a year, to.... even say I actually want a job, I want to build a, a company like I want to be a CEO one day and I was just, like, okay, let me find you somebody to help you do that." (Jessica, DDS Service Coordinator)

## **Safety**

Safety is to ensure that a person is free from harm. Transitioning from a long-term care facility to the community was always about the individual's safety. It was a priority for all the entities involved in the process to ensure that the individual with TBI was

safely served in the community. They did this by ensuring both the environmental and personal safety of the person along the different phases of the transition continuum.

To ensure environmental safety, they safeguarded that the development of the buildings was to code and they were handicapped accessible to the individual with TBI.

“.... what you're looking at is total accessibility. So, when you have things that need to be totally accessible, from showers to, you know, bathtubs to bedrooms to evacuations whether they're, ahmm, you know, French doors that open up on the one level, so you can roll a hospital bed right out of their bedroom to meet the evacuation requirement.... there are all these little considerations that have to be taken care of when you're building a home for, for the ABI population.” (Chip, DDS Service Coordinator)



Figure 8: Picture showing accessibility within the home for individual with TBI to ensure safety.



“Cooktop is accessible for wheelchair users. The oven though seems to be above wheelchair reach. Staff assistance will be needed to use the oven. This again will ensure added safety” (Picture Description).



Figure 9: A fire hydrant placed within the home for safety.

“Building in compliance with safety code and has fire hydrants at various key locations in the home” (Picture Description).

They also ensured emergency preparedness of their staff and followed strict state regulations for safety. For example, by regulation, they were expected to evacuate a building within 2.5 minutes. To comply, residential service providers conduct monthly fire drills with their staff and residents of the home.

“The environment in itself—you have to have at least two egresses, but this home and the homes that they typically build, their bedrooms have their own egress. So, it makes it a lot easier to be able to get them out in less than—because we have 2.5 minutes that we have to evacuate the home and be at the meeting spot.... That’s regulation. It cannot exceed 2.5. It has to be 2.5 or less. We typically do it under—we’ve done it under a minute, all four people with two staff. Yeah, we only do all our drills with two staff. Even though we may have three on, we will only do them with two staff.” (Joe Smith, Residential Program Director)

“....so, a lot of these homes, especially for those who are in wheelchairs or have hospital beds, they might not be in wheelchairs, but they might have hospital beds, they’ll have to do a couple of practice evacuations. A lot of them have

French doors off their bedrooms to evacuation route, so they're going to have to learn how to go through that process because in 24-hour residential it happens monthly...." (Jessica, DDS Service Coordinator)

In addition to making sure that the environment was safe, the personal safety of the individual was also a priority during transitioning. Professional caregivers ensured the safety of the individual with TBI by training staff to properly use and handle equipment during care. They also made sure there was safe administration of medication through close nurse oversight and monitoring of medications. Safety was also ensured by providing good clinical care and assessing for and mitigating any safety risk that may arise due to physical, aggressive behaviors, or other inappropriate behavioral issues occurring in the home.

"She was just concerned with him eating in bed all the time and choking. And we had worked with the nurse, the agency nurse at the time, to make sure that he is getting up to the table in his wheelchair and at least eating meals and snacks..... I said you need to be at the table eating all meals; you cannot be eating in bed, especially peanut butter sandwiches....." (Antonia, DDS Service Coordinator)

"Most of the time because of their diabetes, dementia, and issues through their acquired brain injury... it's not safe for them to do their own meds. Because a) they will forget, So, after we make that assessment, ... whether our nurses think they can self-med and then it gets signed off by their physician and PCP... our staff here only administer meds after their MAP classes.... So, if they pass the written then, they set up a medication pass with the nurse on site, and they go in and take an exam to make sure they can administer properly the five ways using the five rights making sure that you know they know what they are doing." (Caitlyn, Residential Program Director)

".... we allow people to continue to do at least few things—as long as the doctors indicate that there is no medical danger for safety and everything, try to promote them to continue kind of same way of life day today as it used to be before. You know, you want to go out do some stuff, have a little drink, but the doctor has to approve of things. We have to make sure he's not in danger to you in any way medically." (Ubda, DDS Service Coordinator)

## **Personal Needs**

“A need is an undesirable state of affairs, a necessity and a deficit identified through a value judgment and conferring responsibility” (Endacott, 1997). Personal need is need as perceived by the person during their transition from a long-term care facility to the community.

In this study, participants described a process that was central to the person and his/her perceived needs. One of the overall goals of the process was to ensure that such needs were met. Once that was achieved, study participants perceived the process as successful (see Chapter 4). Therefore, professional caregivers and community service providers made it a point first to identify the needs of the person to be transitioned. They did this by making contact and sitting down with the individual to personally ask them or their guardians what they needed.

They also interviewed staff that took care of the person and reviewed the medical records of the person. Furthermore, they observed and assessed them professionally to fully meet the personal needs of the individual. The needs of the individual could be medical, psychosocial, and environmental. Needs could also be more concrete such as medical equipment or specific treatment supplies or care needs. Individual needs could also be abstract, such as “I need to get out of here.” Once needs are identified, professionals with expertise and knowledge put in place services and supports appropriate to meet those needs.

“.... We want to meet with them at different times in the morning, afternoon and evening, so, we can see and understand what their needs are throughout the whole day... What their needs are. We have to know and understand what all the medical needs are. If we have individuals that might have a trach, or they might have G-tubes, what are the specific training that is going to be required from the agency to the staff to support this individual..... We match them according to

their needs. We try to match people close to age, that doesn't always happen as you know, but a lot of times it's the needs that are relevant to the individuals.” (Joe Smith, Residential Program Director)

“And then as far as after that, it's really up to the staff our...my staff to follow through and keep up with what people need and everything else.” (Elizabeth Hapgood, Rehabilitation Director)

“What kind of medical needs are they going to have? .... They need clothing, so we kind of set up that piece of it too and the people could go out with the transitional assistance agency; that might be a provider agency...” (Antonia, DDS Service Coordinator)

“So, you have to think about those things. You have to think about the services that they're going to need when they're in the community because everybody needs different levels of assistance to live ....” (Ava, Facility Social Worker)

Since the emphasis of the process was on the person and their needs, many study participants did not think that having a specific diagnosis of TBI made any difference in their process.

“I think it's person-centered, so some people with TBI may or may not need more.... emotional support, we try to put this in place for anybody who expresses those types kinds of feelings.... I just look at who they are and what they need. I don't look at them differently in....and who they are guides my process, I've just integrated that into my whole person approach to how to guide their transition....” (Jessica, DDS Service Coordinator)

**Sylvia:** “I was wondering if there is anything different that you did for individuals with TBI specifically, when they were moving out as opposed to other diagnosis? Does their TBI play some part in the decision process?”

**Nicole:** “No not necessarily.... we just approached it as any other case looking at his needs. What makes him successful.”

As the needs of the individual were central to the process, providers denied services if they could not meet them.

“They retracted their acceptance of him; they couldn't meet his needs. He is a brittle diabetic, ahmm, he needed, ahmm, glucagon shots and to get him to come back to consciousness, ahmm, he needed two of them every single night to get him back. Ahmm, he has cancer in his.... on his face, skin cancer but they've been

removing it, he's got kidney failure. Ahmm, he's just a hot mess....” (Cassandra, DDS Service Coordinator)

### **Emotional Sentiments**

Emotional sentiment will be defined as a psychological process manifested as an attitude, thought, or judgment driven by a person’s natural instinctive state of mind derived from his/her circumstances, mood, or relationships with others during the process of transitioning to the community. Just as the person was central to this process, so were their emotional sentiments as perceived by the professional caregivers, community service providers, and family caregivers interviewed in this study. Therefore, they tried to ensure that the emotional stability of the individuals with TBI was maintained throughout the process, which further ensured their success in the community. Professional caregivers and community service providers also had the recognition that transitioning was a considerable change for the individuals involved and felt an obligation to make it less stressful.

“Especially somebody with a TBI, because their first process before we can even do any treatment is they have to recognize their disability because they weren’t disabled before. So, we have to work with them on a psychological end on letting them know or getting them used to their new you, which is this now who you are. It’s not who you were, but it’s now who you are, and they have to accept that. And that sometimes can be a challenge”. (Joe Smith, Residential Program Director).

“Support, and when we're doing residential the consumers are very nervous, so emotionally they attach to us. They like, you know, where am I going? Is everything going to be okay? So, we were there not only physically to do all this work but emotionally because it’s a, it’s a big change. They don’t know where they’re going. So, you, you know, you’re there for them all the time, they have tons of questions, their family has tons of questions, and that’s what happens.” (Luz Marie, Transition Coordinator)

“I think there's tons of emotional part of the process. I think that's a huge part of the process because making sure... Like them involving me and like everybody that's involved in the process, you know, from the nurse to the, you know .... it's, and I know it was emotional for him too, nerve-racking, you know, anxiety, like who are these people again. You know, going from one place to another place but knowing that he was going into more of a house setting, a home setting, I think that was easier for him, emotionally” ... (Glinda, Family Caregiver)

They were also aware that unforeseen setbacks in the process could also have some psychological implications for the individual. Therefore, efforts were made to minimize any such negative psychological effect by giving supports and giving them updates, and sometimes putting in place other strategies for communicating undesirable news to them throughout the process.

“Sue White also indicates how important it is to maintain contact with the participants and encourages the Reshab staff to visit them often, at least monthly. They, in turn, visit bi-monthly. My understanding from the explanation she gives is that because it can be a well-drawn out process, the participant gets emotionally down, and it is important to keep their spirits up through regular visits. Checking in and talking to them, giving them updates helps, I believe, in minimizing any emotional distress the process may cause them.” (Field Notes)

“And I think that that is the longest and the most anxiety-ridden time for a person because, you know, they can meet a provider and a home won't be ready for a year, year and a half. So, the waiting time could be that long, or it could be six months, but you know it's a huge window and that's the hardest time for the people that we serve. And that they are waiting to get out of the nursing facilities into a group resident or shared living situation, it's the waiting time.... we try to give them updates as well from the providers that we know, about how a building is going, or renovation is going on the property.” (Antonia, DDS Service Coordinator)

Such efforts made by study participants often paid off as individuals expressed mostly positive sentiments of happiness, excitement, surprise, and disbelief.

“And sometimes what I've seen too is....and I am actually in the process of.... this gentleman I'm working with, and he's kind of become disillusioned because he's like, I've been waiting so long, I've been waiting so long, I've been waiting so

long, but now is at the point where we.... have a tour of the home and have lunch and meet his roommates. He was just about in tears. He couldn't believe this is actually happening.” (Sue Smith, DDS Service Coordinator)

“I was excited, I said what kind of place I come.... It was a nice house, it is a place somebody lives you know.... I am glad I came here.... I am happy here....” (Dave, Individual with TBI)

“They can’t believe it...” (Summer, Transition Coordinator)

Others, unfortunately, did express negative emotional sentiments which often occurred when there was a breakdown in their process of communication, or there was overpromising of services causing disappointment. Sometimes it was merely due to the perceived suboptimal delivery of care.

“.... There were a lot of things promised that didn't happen, that upset me after he got in.... But, the level of care, I'd almost think he'd be better in the nursing home. I'm really not happy with them right now at all.... they said half the time he doesn't want to go so they don't let him go, they just leave him in bed. I'm really disappointed in the program from what they said they were, and the first six months were so good but when he.... from June, I think it was June 15th to December 15th it's been all downhill.” (Mary, Family Caregiver)

“.... some of them have expressed a lot of frustration because things aren't moving as quickly as they would like.... you know, so sometimes things like that and this guardian has been very upset because at the meeting she's like he was promised he was moving in April then it was August....” (Sue Smith, DDS Service Coordinator)

“So, needless to say, I was not happy. I was on the phone with L...a, this cannot happen again, cannot have people working in that house that are not trained to work with J.... a. He's a two on one you know....” (Glinda, Family Caregiver)

### **Wellbeing and Quality of life**

Ensuring the well-being and quality of life of the individual with TBI was a central focus during the transition process. In this study, the well-being and quality of life of the individual transitioning were referenced in many instances by study participants as

an indication of success, as elaborated in Chapter 4. During their transition to the community, the well-being and quality of life of the individual with TBI was achieved by ensuring that the individual's needs, goals, and preferences were respected, and that they were happy and comfortable in the community. Their quality of life was particularly enhanced as they regained independence. Therefore, professionals focused on that as well, so they could be more engaged in the community.

“...It's also trying to figure out with the staff how they can be more, ahmm, how they can be safer but how they can be a little bit more independent, even if it's something as simple as rolling in the bed to help out with dressing versus them being able to dress themselves.... trying to get them, you know, safer and more independent and kinda making them both happy” (Alyssa, Facility Social Worker)

“We do because nursing homes do a lot of—our philosophy in the programs that I open are, we do with and not for. So, we want to challenge them to do as much as they possibly can for themselves....” (Joe Smith, Residential Program Director)

“In the provider world we want to see them independent, and even on the DDS side, we want to see them as independent as possible and not relying on others to do things. So, ahmm she had to learn to do that and that came with a little bit of anxiety for the person, so they had to learn to manage that, but you know they worked with them...” (Cassandra, DDS Service Coordinator)

Professional caregivers and community service providers also ensured the wellbeing of the individual with TBI by helping them support stable health. They did so by checking their health status, giving direct care, and administering their medications.

“We administer all their meds, we are all MAP protocol safe, so our medication administration program is what we use for our MAP. So yes, my nurse will go in, and he'll transition all his meds from the facility. We'll make sure his med sheets are all appropriate and then what they'll do once we learn more about their baseline and their cognitive responsibility, we'll do a med assessment of self-administration.” (Caitlyn, Residential Program Director)



Furthermore, transitioning from the skilled nursing facility into beautiful and handicapped-accessible homes in the community gave them a new meaning to life, and helped improve their quality of life as well.



Figure 10: Front entrance to one of the group residences with beautiful curb appearance.

“This house is in a very quiet and suburban location. The atmosphere on a quiet Tuesday morning was so serene and very relaxing. House has a level entrance to allow for easy wheelchair access. The beautiful landscaping gives it great curb appeal and a homelike environment. It is Halloween, and the house is decorated with a picture of a ghost on the door.” (Picture Description)



Figure 11: Showing a comfortable living area within the group residence.

“House has a second living area. Tastefully decorated with soft tone green upholstered chairs. These chairs look and feel very comfortable. Unlike the main living room that has a big flat screen TV on the wall, this area is quiet and peaceful and overlooks the backyards. The large windows allowed so much light that gave it added ambience. It certainly is a great room for meditation and reading. It will surely enhance the quality of life and wellbeing of these participants.” (Picture Description)

The professional caregivers and community service providers made it a focus to get them socially engaged in the community by encouraging them to take part in day programs, volunteer activities, and other programs in the community.

“We like to work with the person themselves to see you know, do they wanna join a volunteer group.... do you want to become a professional dog walker, or do you want to volunteer at a home... but I give them the ideas that they could, you know, that they can do...? (Jessica, DDS Service Coordinator)

Professional service coordinators showed that they were vested in making sure that participants were happy, comfortable and had all the tools they needed to enrich their lives.

“I feel through the ABI, and, ahmm, the MFP program is true happiness and making them realize that life can go back to what you want it to be based on your

level of engagement. .... this makes you happy, traveling, being engaged with your family, earning money. So, then I sit here, and I brainstorm, and I say to you, are you interested in working, are you interested in volunteering, are you interested in your own business.... So, that person guides literally everything from the moment you engage with me, you are the expert from beginning to the end. That's it." (Tina Marie, DDS Service Coordinator)

### **Summary**

The phenomenon of "it's all about the person" emerged during this study. In this chapter, an extensive description of this phenomenon is reported. The "it's all about the person" phenomenon was described by study participants as the individual's choices, human rights, goals, needs, safety, emotional sentiments, wellbeing, and quality of life. This phenomenon steers the transition process from the pre-transition stage through the transition phase to the post-transition phase. It was also central to the transition management process engaged in by the individual with TBI, the family caregiver, and community service providers. These processes include coordination, communication, team collaboration, relationship building, and social engagement and will be described further in Chapter 6. How this phenomenon steers the transition process will also be discussed later in Chapter 7.

## **CHAPTER 6**

### **THE PROCESSES OF TRANSITION MANAGEMENT**

#### **Introduction**

Transitioning management is defined as the processes individuals involved with transitioning an individual with TBI from long-term care facility to community engage in to ensure successful outcomes. These processes, as described by the individual with TBI, their family caregivers, professional caregivers, and community service providers in this study included: checking in, planning, communication, team collaboration, coordination, relationship building, and social engagement. The collaborative team in this study described these management processes, with the person being central in their decision making and actions. These transition management processes occurred along the continuum of the transition process. The transition management processes occurred individually with teams involved in the transition process and collectively by the inter-collaborative team. For example, planning processes occurred within each team and collectively as a collaborative team. In this chapter, an explicit description of communication, team collaboration, coordination, and relationship building will be reported. The checking in and planning processes, however, will be discussed in Chapter 7 as part of the pre-transition phase of the transitioning process. Social engagement will be described with the post-transition phase, also in Chapter 7. This is because these processes occur prominently in those stages of the process.

## Communication

Communication was a key process used by the collaborative team in managing the transition of the individual with TBI from the long-term care facility to the community. Communication occurred throughout all phases of the transition process and involved three main elements including the patterns of communication, the reasons for communicating and the mode of communication used during the process of transitioning to the community. Figure 12 below shows these three elements and the codes associated

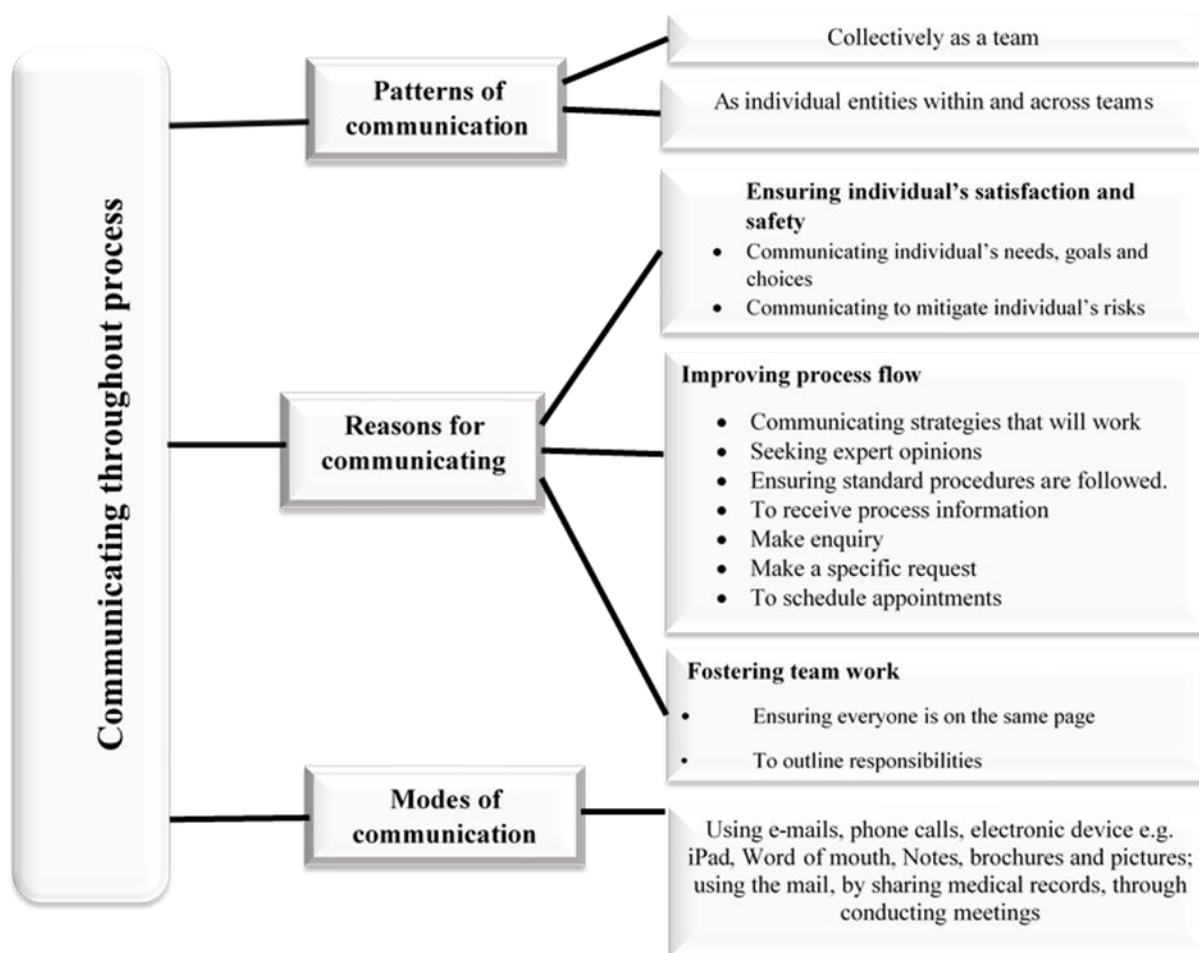


Figure 12: The elements of communication.  
with each of them. Each element and their corresponding codes will be further elaborated upon.

### **The Collaborative Team**

Communication occurs among all key players who together make up the collaborative team. The collaborative team as depicted in Figure 13 is made up of the individual with TBI (ITBI) and/or legal guardian, the community service providers (CSP) involved at the time, service coordinators from DDS (SC), the long-term care facility (LTF), and family caregivers (FC). In this process, the service providers from DDS take the lead in coordinating the entire process through the phases. However, the person is central to all the decision-making processes that the collaborative team makes. Each entity that makes up the collaborative process are also independent teams within their organizations and have a leader. For example, the team from the long-term care facilities is made up of the social worker, the nurses, and the therapy staff. In their team the social worker functions as the lead person. The individual with TBI and legal guardian and/or family is also considered a team in this process, with the ITBI as the lead in that team. Unlike the other teams, there can be more than one community service provider team, depending on the needs of the person. Most often, the residential group home providers, also regarded as a community service provider, is present as an independent team. Other agencies are also involved in providing community services. For example, durable medical equipment may also be present with their team and a leader at all transition meetings. The larger collaborative team is also interdisciplinary in nature and some, but not all, individual members of the team could belong to different professional disciplines. The complexity of the team further complicates the pattern of communication as is depicted in Figure 7.



Figure 13: The collaborative team involved in the transitioning process

Several DDS service coordinators interviewed gave clear descriptions of the make-up of some of the teams they worked with during the transitioning process. What was interesting was the fact that these service coordinators set up their teams around the needs of the individual with TBI who was transitioning. Therefore, the makeup of each intercollaborative team varied with each individual with TBI who transitioned.

“At that first transition meeting ...we’ll have the provider agency at the meeting, we might have someone from our nursing team at the meeting, may be our psychologist, at the meeting and like I said the provider, their whole clinical team.” (Antonia, DDS Service Coordinator)

“What I mean by the whole team is the staff from the provider agency who’s going to be doing the residential part. I’ll send up list everyone on that team, that means the program manager, the program nurse, if there is a therapist that can do the clinical part on that team, I’ll invite them. I will also invite an equipment person from the outside...” (Redsox, DDS Service Coordinator)

“Yeah, so to set up the team for transition meeting.... we’ll have him, we can have their unit ---may be the nurse, the unit manager, if there are rehab people, we want the rehab team as part of the meeting. And also, if the individual has a guardian or a family member involved or anybody around you know, families....” (Ubda, DDS Service Coordinator)

### **The Patterns of Communication**

The patterns of communication are defined here as the structure of communication links among the transitioning teams. Communication was complex and followed a network pattern where individuals communicated collectively as a team among and across the different entities or organizations. As shown in figure 8 below. Communication also occurred individually among members of the collaborative team. Study participants described many instances that they engaged in communication across teams during the transition process. For example, one transition coordinator describes how she engages in communication with the individual with TBI as well as long-term care facility staff.

“...when I go I don’t just sit and talk to the consumer [individual with TBI] I talk to-to the nurses you know, ‘can you tell me more about this?’, this is why I’m here, but many times they say oh here’s the chart and I’m like I don’t want the chart.” (Luz Marie, Transition Coordinator)

Another DDS service coordinator described communication with a residential group home provider and with the long-term care nurse.

“We have a lot of increased communication between myself and the provider and the floor nurse over there.” (Cassandra, DDS Service Coordinator)

Sometimes communication across teams was matched up between same professions. For example, the nurse from the residential provider team, communicates with a nurse at the long-term care facility.



“I usually have the nurse from the provider [group home] communicate with the nurse at the nursing home.... Nurse to nurse, yeah...” (Ubda, DDS Service Coordinator)

Communication within independent teams occurred at staff or house meetings. A residential program director and the director of rehabilitation for MAB, described communication with their team members to discuss issues that will ensure successful transitioning outcomes.

“Yes. I meet with my staff usually every week and we go over .....I have one house meeting typically a month, where it's a house meeting, but I sit with a lot of the staff individually and go over ways that we can make it work”. (Joe, Residential Program Director)

“we have a staff meeting where everybody who works for the waiver system sit down in our office and kind of look at things as a global Ahmm picture” (Elizabeth Hapgood, Rehabilitation Director)

### **Mode of Communication**

The mode of communication varied throughout the phases of the transition process, and they included emails, phone calls, word of mouth, writing notes, regular mails, sharing medical records, giving out brochures and pictures, and conducting meetings. The use of email was often the most preferred means of communication that members of the team used. Conducting meetings was also common.

“But these guys email me ...at least on a weekly basis with stuff that you know isn't going well or needs to be addressed or needs to change as far as our communication with the house or what the case managers need.... Service coordinators need to know what is going on. .... Ahmm and then in addition to that, every other month we have a staff meeting where everybody who works for the waiver system sits down in our office and kind of look at things as a global picture.” (Elizabeth Hapgood, Rehabilitation Director)

## Communication Occurring Throughout the Transition Process

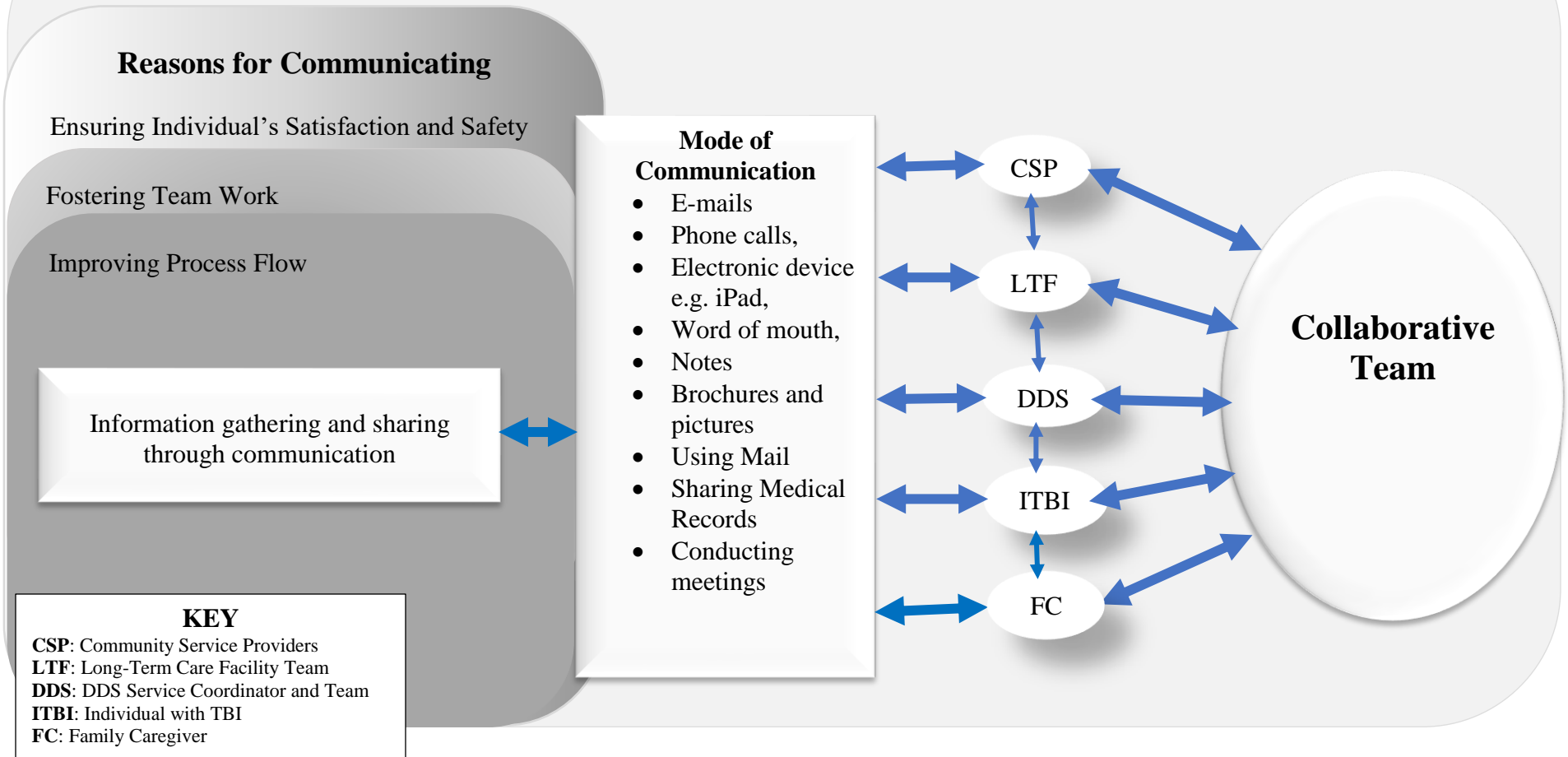


Figure 14: Communication as it occurs during the transitioning process.

“I like to do, is after the first meeting, send out an email to the team kind of outlining everything we had talked about.” (Sue White, DDS Service Coordinator)”

One DDS service coordinator indicated that using email for example was often helpful in continuing and following a chain of communication. It also served as an audit or paper trail to ensure accountability among team members. In addition, she felt that the use of email was a faster mode of communication.

“I may start the process, and a new coordinator may be coming in to take over the process so having those email chains where you can just loop that person in, they now can feed off of all the stuff that's been happening before. So, I would say out of all the communication, the email is the most consistent, probably top priority for us just because it keeps a paper trail and people respond a lot faster through emails these days.” (Tina Marie, DDS Service Coordinator)

Word of mouth was another mode used in communicating especially during face to face meetings at check in and also during outreach for referrals.

“We can get them [program referrals] either through, you know, through word of mouth, through social workers but also the service coordinators at DDS and MRC also do outreach, so we get direct referrals from them as well.” (Kennedy, Transition Coordinator)

Other team members communicated by phone. Talking by phone was used when communicating with the families and guardians. This was especially true for those who had busy schedules and could not always be available for meetings or face to face communication.

“They [were]...and if I couldn't go, they would do a conference call because I work at night. It was hard for me sometimes to go all the way down there, but yeah, we did conference calls.... If he tells me something that's going on, that I haven't been told about, I just email somebody, and they get back to me about it.” (Glinda, Family Caregiver)

“Oh yeah, yeah, we had a -we had a lot of meetings, a lot of phone calls a lot of correspondence. I was trying to get it together.” (Mary, Family Caregiver)

In many instances, communication was done by sharing documents such as medical records among the collaborative team.

“...I tend to photocopy the entire nursing home chart .... So, we send all that over....” (Cassandra, DDS Service Coordinator)

“After the first transition meeting, us as a service coordinator, we send out notes as to what we spoke about, what everyone’s responsibility is during the transition process, so I send that out.” (Rudy, DDS Service Coordinator)

Communication is sometimes done using electronic devices. Individuals with TBI sometimes do better using these assistive devices to communicate. Therefore, the staff brings assistive devices in to help give them a visual representation of what is being described to them.

“In some of the cases that I’ve worked with the provider agency have brought an iPad, and they have been able to show the individual here's the house, here are the rooms.” (Sue Smith, DDS Service Coordinator)

### **The Reasons for Communicating**

Members of the collaborative team talked among and between themselves as individuals and as a collective team throughout the process. In this study, the reasons communication happened varied. However, the most common reasons were to: 1) ensure individual’s satisfaction and safety, 2) foster teamwork, 3) improve process flow. These reasons will be described below.

### **Ensuring Individual's Satisfaction and Safety**

Communication occurred among the team members to ensure that the individual's needs were met and to ensure their safety. In communicating, the DDS service coordinators were able to find the best provider agency that could meet the needs of the individual. Furthermore, through communication among the team members, the individual's preference became known, which helped them make informed and good planning decisions to ensure the individual's satisfaction.

“Let's see.... I think one of the reasons we hold transition meetings, is to make sure that any concern that the individual has, is being addressed, and I think naturally—for the majority of people they have a lot of questions, they're pretty apprehensive, but we answer them during the meetings, to make sure that the transition is a smooth one for them.” (Rudy, DDS Service Coordinator)

One family caregiver of an individual with TBI described how she communicated with the long-term care facility and other team members about her son's preferences and needs to ensure that they were being met throughout the process of transitioning to the group home. This she did to ensure the safety of her son.

“Ahmm, well, I got the letter saying he was approved and then it was a matter of speaking with people about where we wanted him to go. What area of the state we wanted him to go? And I wanted him up here closer to us.... Like, I spoke with the social worker lady, you know, quite often. I'd call her if I wanted to know something or you know, we have to make sure that, they know that he has this and this and this.... Like, make sure this goes with him, and this goes with him, and makes sure they know he has to, you know.” (Glinda, Family Caregiver)

### **Improving Process Flow**

Team members communicated almost constantly throughout the process. They did so to ensure that the transitioning process was progressing smoothly and that the collaborative team and its members were making progress with their assigned tasks. They

also communicated to check on the status of the individual, e.g., their medical stability. They also communicated other pertinent issues necessary to steer the process forward. The communication among the team included obtaining and giving updates on progress made throughout the process. In addition, they communicated to build relationships and mutual trust, which helped with the process flow and enhanced individual's satisfaction. Study participants described engaging in such communications.

“We meet with all of our providers on a quarterly basis. We get updates, you know, on the quarterly basis but in between that we'll get updates as well about how a building is going or renovation is going on the property.” (Antonia, DDS Service Coordinator)

“I will also call the house to make sure—I usually call a day before the day of discharge, to make sure everything is delivered.” (Redsox, DDS Service Coordinator)

### **Fostering Team Work**

Communication was also to foster teamwork. This was important, as there are many teams involved in the process. Therefore, to ensure that every member of the team knew what their role and responsibilities were, it was critical to engage in constant communication with them to ensure a smooth and seamless process.

“I will type everything up at that second transition meeting and send a summary of all the tasks, the duties that each entity has. Whether it is the nursing home getting medical supplies, signing orders, making sure that they have all their PT equipment, whether it's a new wheelchair in the works, a new walker, a shower bed, it all depends on the person.... Ahmm, the providers, the nursing home even though its summarized in the body of the email, they get the actual move into community document, so it's very detailed. It's a 20, 20-page document, it's very lengthy, but it's filled out, every section is filled out. Ahmm, what services are planned? Ahmm, what equipment they need? When they transition, who is responsible for it? Who is going to be coming to train with the nursing home on specific needs? Whether it's transitioning, standing and pivoting, moving to the bathroom. If there's something specific, they'll train with.... PT/OT staff should be doing those things.” (Cassandra, DDS Service Coordinator)

“So that’s normally where I start off with that first transition meeting, is just to get everyone on the same page, and I send a thread out, an email with everyone’s name on it so that we’re all looking at the same email.” (Redsox, DDS Service Coordinator)

### **Team Collaboration**

Team collaboration was another key process used by professional caregivers, service coordinators, the individual with TBI, and their families during the transition from the long-term care facility to the residential group home setting in the community. Team collaboration is when two or more entities work together to achieve a common goal. In this study, the elements of team collaboration were: having a team, engaging in shared decision making, problem-solving, sharing tasks, working with experts, and relationship building among members of the collaborative team (see Figure 15). A description of the elements by study participants will be further presented. The element of having a team has been earlier described under the heading of “the collaborative team” above.

### **Shared Decision-Making**

Shared decision making is an approach where the collaborative team makes decisions together drawing on their different expertise, skills, and experiences. In this study, the individual with TBI and legal guardian was central to the decision-making process. Being essential members of the collaborative team and experts in their rights, the professional caregivers and community service providers closely engaged with them during the planning process and throughout the continuum of transitioning. They did this

through frequent communication, giving updates, providing options, and seeking their preferences. Engaging in shared decisions helped to ensure patient satisfaction.

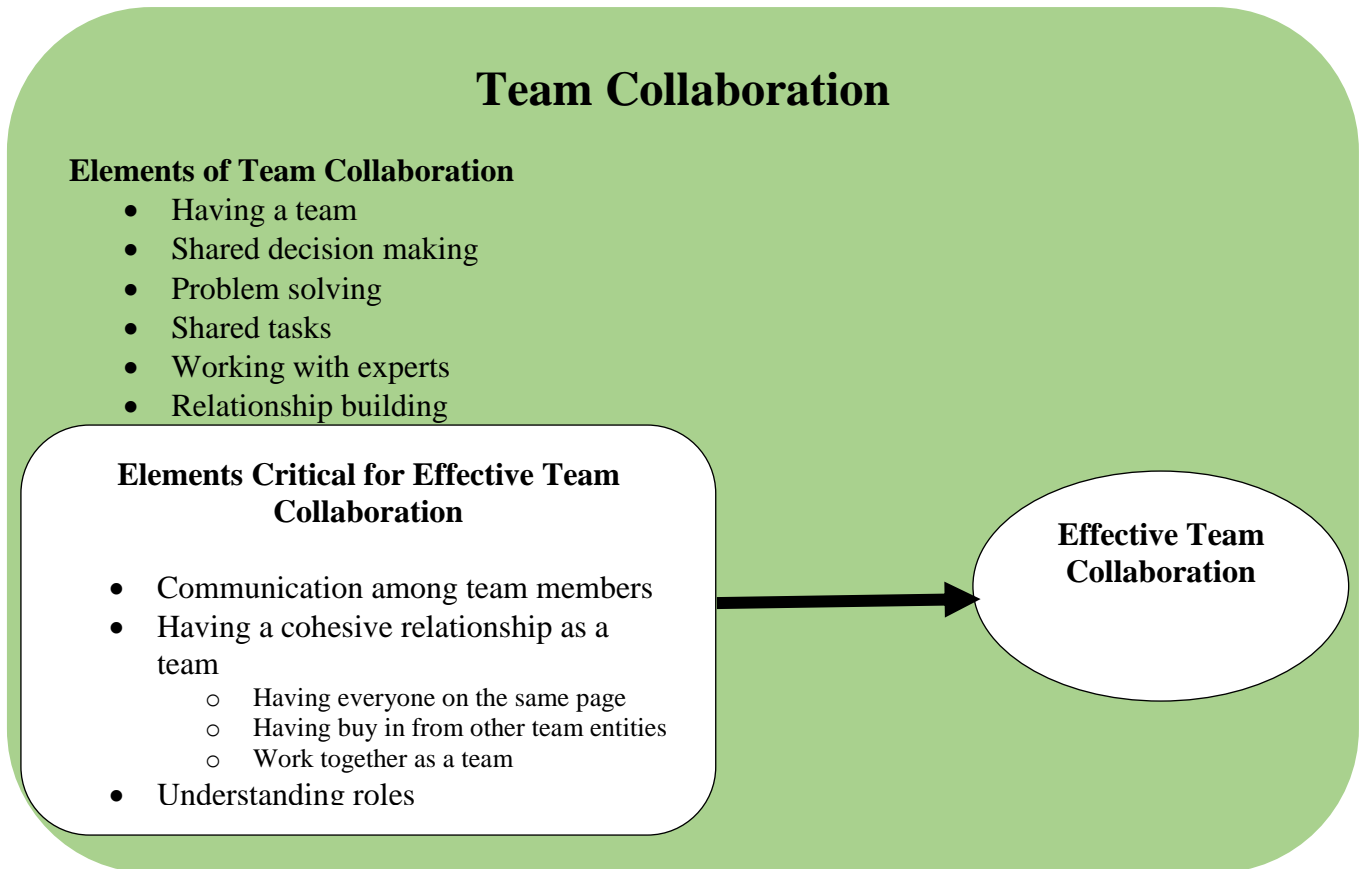


Figure 15: A model showing the elements and conditions of team collaboration.

“Right from the beginning, nothing, really nothing took place without approval. ... I said they made him such a big part of all the decisions, that for him it was a no-brainer.” (Glinda, Family Caregiver)

“I go back, and I talk to them, and I offer it to them. Sometimes they say no (laughs 2:38), it's not in the area that they want or it's too far from the area that they want so then we come back and meet as a team...” (Cassandra, DDS Service Coordinator)



The shared decision process was not only engaged in independently with the individual with TBI, but it was also collectively done with the team to brainstorm and problem solve.

“We come back, and we meet as a team, and we try to come up with a grouping of individuals who wanna live in the same areas, who are interested in the same things.” (Sue White, DDS Service Coordinator)

“Once we get those decisions made, as a collective group, obviously we are continuing to go out and monitor the persons, you know, health and stability within the nursing facility because that’s always subject to change.” (Jessica, DDS Service Coordinator)

“I mean, there were meetings the team came out, and we had additional meetings where he was able to voice any concerns or his interest, things that he wanted and got some questions answered, so I think we had a couple of transitional meetings.” (Rose Quartz, Facility Social Worker)

### **Problem Solving**

In this study, problem solving was found to be one of the elements that the collaborative team engaged in during the transitioning process. The team comes together often to identify any problems and find solutions collectively. This was necessary to foster a smooth and seamless process. During problem-solving, the individual’s wellbeing was always central to the thought and decision-making process.

“And we’ll look and try to brainstorm as a group, so all of the service coordinators and the program manager and sometimes the nursing will come in and sit down and start to plot out, based on their medical needs, where they best fit.... ah, in a residential group home in some respects. So those are.... that’s the path we take....” (Jessica, DDS Service Coordinators)

“Working with the group home after the move of the participant or person from the SNF, according to Sue, is an ongoing process. She talks about it as being a collaboration, and as a team, they continue to work to solve problems as they arise.” (Field Notes)

## **Shared Tasks**

Another element of team collaboration described by some participants in this study was ensuring shared tasks. Transitioning an individual with TBI is complex and has lots of moving parts. It was, therefore, important to share the tasks among the collaborative team, mostly through delegation. Each entity within the larger collaborative team also had an expected task to perform during the process, for example, the residential group home providers were to ensure that furniture and personal needs were obtained before the transitioning. The long-term care facility also had their shared task of ensuring that medical supplies and equipment were ordered, and medication orders in place for the transition. Sharing tasks was to ensure that the needs and goals of the individual with TBI were met and to foster a smooth transition process.

“I will type everything up at that second transition meeting and send a summary of all the tasks; the duties that each entity has. Whether it is the nursing home getting medical supplies, signing orders, making sure that they have all their PT equipment, whether it’s a new wheelchair in the works, a new walker, or a shower bed, it all depends on the person... The provider, ahmm, will at that time if they haven’t already done so, start purchasing furniture, clothing, lamps, curtains, anything that they’re going to need when they transition out. If they don’t have any of that, we don’t do a discharge...” (Cassandra, DDS Service Coordinator)

“We do try strongly with the full team to get those things in place, and then that’s kind of where it does fall onto the.... [different providers]. You know.... the medical equipment and everything, we, getting it there, you know, having those people, the different providers that we have.... that we work within the waiver getting those beds and stuff there on the first day.... You know, making sure that we’ve reached out to any day services if they want to start day services....” (Jessica, DDS Service Coordinator)

“.... And you have people that are delegating who is going to do what, for that person, who makes that really nice.” (Nicole, Facility Social Worker)

One social worker described that being assigned tasks for her team was helpful but felt that the job was sometimes too much.

“This is what our team is doing, this, this and that was, that was helpful you know, but it is sometimes, it is still quite a bit.” (Rose Quartz, Facility Social Worker)

### **Working with Experts**

Working with experts was an element of collaboration described by members of the team. The team relied on the expertise and experiences of each other to problem solve and make the best decisions for the individual with TBI transitioning from the long-term care facility to the community. The individual is present and part of the team since he/she is also regarded as an expert.

“So, I look at myself as a coordinator as just a tool, and I cannot be used unless the expert picks me up and integrates me into their life.... And the expert would be in this case the individual person.” (Tina Marie, DDS Service Coordinator)

As an expert and part of the collaborative team, the role of the individual with TBI/legal guardian was to voice their needs, wants, and concerns, which was critical to ensuring patient satisfaction.

“...The residential provider, they’re at the meeting because the individual is moving to one of their facilities. The nursing facility is, of course, important for them to be there, in case there is anything they need to do—you know that can be setting up OT or PT assessments before discharge. Others, the person’s, parent and guardian if they have one, are there to voice their needs and wants and concerns, they have any questions, they can ask, and you know, we try to answer it. And me, you know, working for DDS, I’m there to facilitate the process, to make sure everything goes smoothly.” (Rudy, DDS Service Coordinator)

The expertise of all other members was also essential and was sought through collaboration throughout the process.

“The transition meetings involve a large group of people to address all the essential needs of the participant upon transition, e.g., equipment needs, etc. At this meeting all the needs of the clients are identified, clinical, psychosocial, etc. and strategies to meet those needs are formulated and discussed as a team. The expertise at the table is utilized, for example, to determine the best type of equipment needed....” (Field Notes)

“We like to speak with the specialties, occupational therapy, speech therapy, and physical therapy just to get.... especially with.... people who are in wheelchairs. Just because we wanna make sure that the specs that we get for the wheelchair and for the one that’s going to be ordered for the community is accurate, that its appropriate and it's personable....” (Jessica, DDS Service Coordinator)

“The OT to make sure that all the equipment's in the room are available, and the house and the bathroom will be big enough and accommodate. Yeah, so it’s every discipline has their counterpart.” (Rickie, Facility Social Worker)

### **Relationship Building**

Relationship building was described as a desirable element of team collaboration as it fosters a sense of oneness and trust among members of the team (“we are all in it together”) and helps to foster a smooth transition to the community. In this study, relationship building collectively, as a team, was sometimes difficult.

“Its.... if that director and that staff and that nurse and whoever has connected, we've all connected, even though we're different, we're all working towards a common goal and if that hasn't happened, it really makes it difficult.... I don't have that connectedness, I don't have that buy-in, I don't have that...I don't have any of that. None of the relationship with any of the people there.” (Isadora, Occupational Therapist)

However, individually among the team members, they formed strong relationships to ensure a smooth process.

“So, ahmm, our relationships with those vendors are very important (laughter), so I have one vendor that I always go to right now, and she is.... they’re phenomenal.... They just said that they had ordered it and it was to be delivered, and it didn’t show up. They moved him, picked him up, and they said it was supposed to be there that day, it never showed up.... So, I had.... I have a good relationship with another provider...another vendor, and I called her, and she was

able to get me a bed immediately... I use Easter Seals only because I have a good relationship with, ahmm, the main guy (laughter), I use him a lot, so he's very responsive to me, and he gets them out there really quickly....” (Cassandra, DDS Service Coordinator)

Though relationships were difficult to build collectively as a team, some teams were successful. A community service provider, who is also a member of the collaborative team did attribute the successful transitioning of a complex individual to their relationships with the long-term care facility team led by the social worker and another community service provider CHARM (a durable medical equipment provider).

“So... I mean, like literally, the first person transitioned home with the G-tube and no food. Like I didn't, we didn't really know what we were doing. But, then saying that none of us are clinicians, we were so successful, and I'm, and I think it was because of our relationship with social workers and CHARM (a durable medical equipment provider)....think that's why their....MFPs has been so successful as opposed to like you know, the one care model, is because of like the, the intermediary or interdisciplinary care team, you know, that like everyone is on....the same page, we're all in it together as opposed to....” (Kennedy, Transition Coordinator)

### **Achieving Effective Team Collaboration**

Despite the presence of strong elements of team collaboration in this study, team collaboration was not perceived as always effective by the study participants, as they run through many barriers during the process, as elaborated in Chapter 8. They did, however, identify critical elements that they felt were essential for the team to have to be able to achieve stronger collaboration. These necessary elements included: effective communication and having a strong and cohesive relationship often expressed as “work as a team”, “being on the same page,” and “having a collective buy-in as a team.”

“If the house isn't helping out and buying in and taking them to their doctor's appointment those wrist braces aren't being received. So, you know their co-

operation, and their acceptance of what we're doing is huge..." (Alyssa, Facility Social Worker)

"There is no straight-up way of doing the transition, but communication is the major thing and trying to bring the team together. Once everybody gets a sense its teamwork, that's when it usually works. Once we call our self, Team Joe, that usually works perfectly. But to get there, it can be a little tricky sometimes...So yeah, so successful transition is to have the team working together" (Ubda, DDS Service Coordinator)

"Very major! Communication is so major in this one so that you could put an arrow all reconnected, connected, but communication is major." (Tina Marie, DDS Service Coordinator)

"It is as simple as that, but when it comes to a group home transition, it is, it's a whole team, it's awesome." (Rickie, Facility Social Worker)

"So, usually before we transition someone in we have a staff meeting, so, we have all of our staff on the same page that you know we'll have a staff meeting in the morning" .... (Caitlyn, Residential Program Director)

"MFPs has been so successful as opposed to like, you know, the one care model, is because of like the, the intermediary or interdisciplinary care team, you know, that like everyone is on the same page, we're all in it together as opposed to...." (Kennedy, Transition Coordinator)

They also perceived one's understanding of his/her role as a member of the team as critical to effective collaboration, such that when it was lacking, it affected the team negatively.

"I myself come from a residential background where I've managed residential homes. So, when I'm sitting in these meetings in between the provider agency and the skilled nursing facility, I realize that these two entities don't understand how each....You have nursing homes coming saying we don't do that, we don't do this, we don't....So, whether or not the social workers are aware of their job but because they're participating in the waiver, I found that the biggest barriers are that they don't know what is to be expected of them...." (Tina Marie, DDS Service Coordinator)

## **Coordination**

Coordination was a key process that occurred throughout the transition process. In this study, coordination as described by the DDS service coordinators, was about taking a lead role and organizing all the different entities involved in the transition process to work together as a collaborative team. It was also about organizing and ensuring placement of services for the individual transitioning to enhance a successful transition process. The coordination process occurred through continual communication with all the entities, as earlier described. It also was enhanced with effective planning strategies. In this study, the process of coordination was described by participants in the context of communication and team collaboration, as these processes often occurred concurrently, and not necessarily distinct from each other (see Figure 16). During transitions, it was critical to get the entire team on “the same page,” so that the process would be smooth and seamless. To accomplish this, DDS service coordinators engaged in coordination with the transition entities through communication and organizing several meetings at the pre-transition phase, through the transition phase, to the post-transition phase of the process. At the pre-transition, which was also a preparatory phase, coordination was critical, as it was the period where efforts were being made to identify individual’s needs and goals and organize appropriate services and supports to meet those needs in the community and ensure the individual’s satisfaction.

In this study, several service coordinators gave some insights into some of the coordination processes that occurred during transitioning. They organized and put together a collaborative team by sending out invitations and conducting transition and service plan (ISP) meetings.

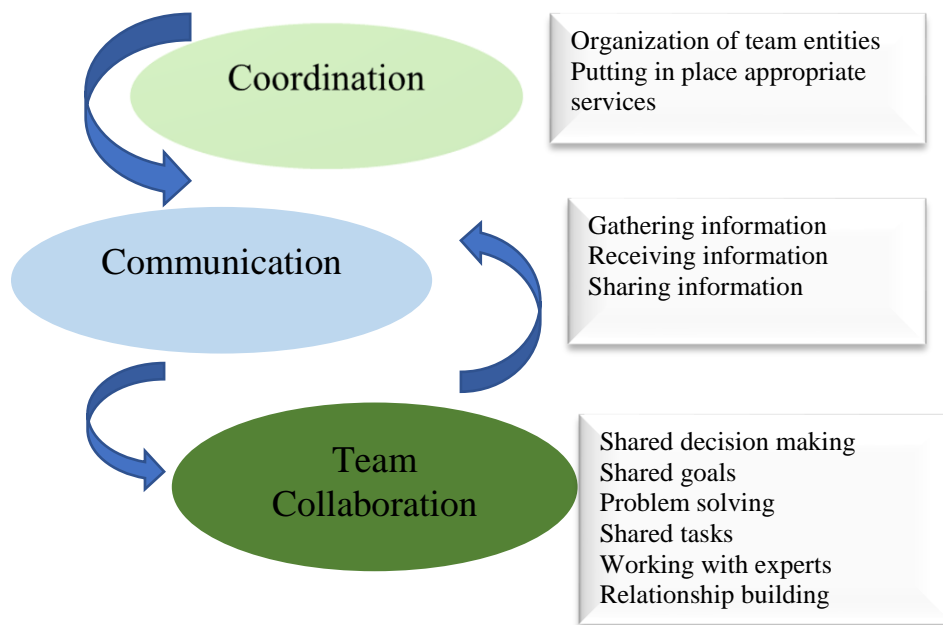


Figure 16: Coordination, communication and team collaboration within the transition process.

“I’ll invite them. I will also invite an equipment person from the outside. Usually, I use Life Supply, is the company that I use. And because I find it that it’s easier to order equipment from someone from the outside than it is actually to do it through the nursing facility. ... I also invite our DDS nurse to come with us.... But if I have a family that’s very, very involved, I invite them to all of the quarterly meetings; I invite them to the service plan....” (Red Sox, DDS Service Coordinator)

“And basically, for that to happen, you know, everyone has a role, everyone has the things they got to do, whether it’s coordinating therapies or scheduling and finding a PCP, finding a moving company, if needed...” (Rudy, DDS Service Coordinator)

They also organized services, by sending referrals out to appropriate agencies based on the needs of the individual with TBI and ensured that these services were put in place before their transition from the long-term care facility to the community.

“.... physical equipment and things of that nature that we need to put in place. We traditionally contact, -- what they call a transitional entity that helps, you know, they’ll come in and help them...the individual that we are moving start to build their life back up. So, their needs like clothing, winter coats, toothbrush, you



know, all those kinds of random knick knack things that we don't think about traditionally.” (Jessica, DDS Service Coordinator)

“So, we'll get that stuff underway.... Depending what their skilled nursing needs. Some agencies provide different levels of nursing for their houses. So, if it's someone that is going to be more medically intense, we look for an agency which provides that...” (Antonia, DDS Service Coordinator)

“.... Normally, I have all these referrals. I do a referral for the day program, I do a referral for an agency that is called Massachusetts Association for the Blind. They're an agency that come—they will come to the house, and they will assess the person's medical equipment...” (Redsox, DDS Service Coordinator)

### **Relationship Building as a Transition Management Process**

Building relationships is a process of identifying and forming a connection with an individual in a way that is of mutual benefit to both parties involved. Relationship building, as described by study participants, was a process that started with making contact with the individual and staff, and engaging in professional interactions with them through communication and information gathering to get to know the person and, subsequently, develop rapport (mutual trust and respect). Also, findings from this study showed that relationship building started at the checking-in phase of pre-transition and became more elaborate as the transitioning progressed. Towards the end of the pre-transition phase, and during meet and greet phase, social interactions were introduced as an added means of relationship building, besides professional interaction. Social interaction during the meet and greet phase was to introduce individuals to housemates and briefly foster socialization with them, their families, and staff at the residential group home. It was also noted in this study, that relationships initiated at this stage of the process were further nurtured through the transition (move in) phase, to post-transition (living in the community) phase. At the post-transition phase, relationships were

strengthened as individuals had increased interactions with staff and peers through frequent conversations, playing games, and engaging socially in various activities such as outings to movies, dinners, church, etc. With strong relationships came the development of mutual trust and respect, which was helpful in promoting happiness in the home. Relationship building, as it occurs in this process, is depicted in Figure 17 below.

### **Visiting the Person**

The initial stage in relationship building as described by study participants was about making contact with the individual with TBI. Making contact was often through face to face visits with the individual at the long-term care facility. This was done to establish some familiarity with them. While visiting with the individual with TBI, professional caregivers and community service providers also made contact with the social worker and staff at the facility to initiate some familiarity with them as well.

“Well, typically we would just get the call and then we would set the time with the nursing home to go and visit the individual that’s being transitioned or in the idea of being transitioned. (Joe Smith, Residential Program Director)

“Then I go down and see the consumer. I usually stop and see the social worker first and let her know that I’m there, and why I’m there.” (Luz Marie Transition Coordinator)

“We go out, we meet with the person for the first time, and we just get a sense from them...” (Sue White, DDS Service Coordinators)

“Yes. She’s from DDS. She would then kind of reach out, introduce herself to us. She’d establish the first meeting....” (Nicole, Facility Social Worker)

“He also indicates the importance of the Reshab staff going out to meet with the person before actual transition. Having a meeting with the individual, he says, is to have some familiarity with the person transitioning which he indicates “smooths” the process.” (Field Notes)

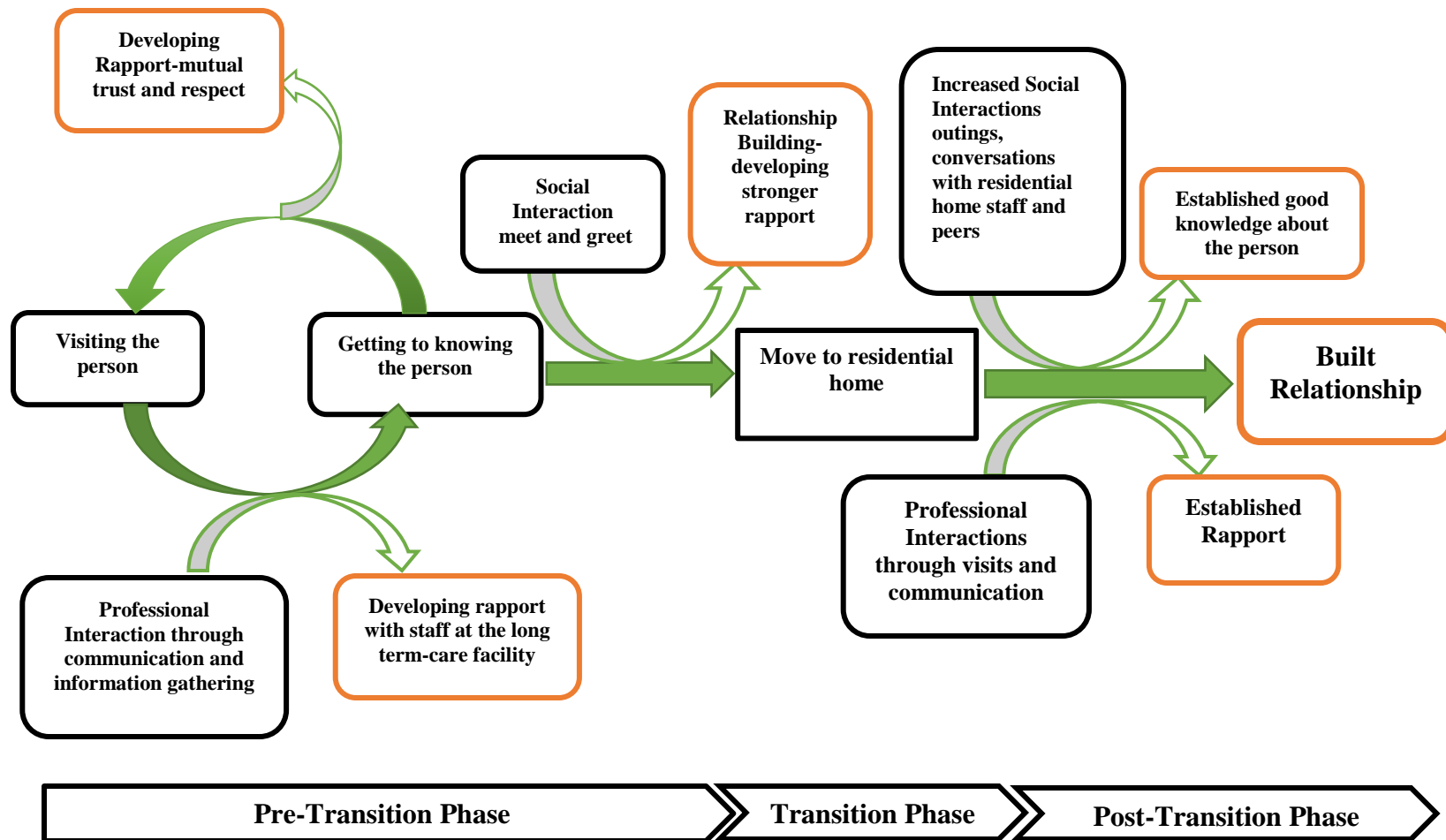


Figure 17: The process of relationship building during transitioning from long-term care facility to community.

During these visits, professional interactions take place through communication. During such interactions, professional caregivers seek and gather pertinent information about the individual. These visits are regular and are made on average every three months by the DDS service coordinators. Other professional caregivers and community service providers also engage in a similar process, to build a relationship with the individual.

“Yeah, that's, we visit every three months, quarterly, and we can just check in to let them know any status updates, if we've presented their referrals to any providers at this point in time. Meeting the providers out at the facilities with them, to get to know them, to interview them and things like that, with the guardians or health care proxies, etc.” (Antonia, DDS Service Coordinator)

“Let's say the person is accepted. I usually hear from my case manager that's been assigned to that person. Set up a meeting, ahmm, they come in to meet with me, and, we'll bring in the resident, ahmm, and kind of have the initial intake meeting with the new case manager. So that way, the person knows who they're gonna be working with and knows who the contact person is up in the facility, ahmm, gets any paperwork, copies of the record, anything that's needed, and then they go from there.” (Rickie, Facility Social Worker)

Some community service providers make more frequent visits to help them have a more in-depth knowledge of the individual and his/her needs.

“Once we do that, we would then set up times on a weekly basis to go back and meet with the individuals. We want to meet with them at different times in the morning, afternoon and evening, so we can see and understand what their needs are throughout the whole day. It only makes sense to actually do that, because the morning might be a little bit different than the afternoon, and afternoon and night and so forth... And we usually try to schedule staff to go on a rotating basis” (Joe Smith, Residential Program Director)

“Once we have that, it's.... the expectation is that the agency who's accepted the person sees them monthly.... we have to see individuals bi-monthly no matter where they are, whether they're at the nursing facility or if they're out.... if they've been placed. So, they.... have regular contact....” (Sue White, DDS Service Coordinator)

In a few instances, contact with the facility staff did not occur, and that often-caused animosity between the professional caregivers or community service providers and the social workers, at the facility and impeded relationship building.

“I was in a nursing home, and I left my office for something and noticed these two-weird people walking around my building. I had no idea who they were and what they were doing, and I stopped them and asked them to identify themselves because they had no name tags on or lanyards or anything to identify themselves. And they told me about the program, and I said wow, that sounds super awesome, don’t ever come into my building again without having identification on your body, and come in to talk to me first....” (Rickie, Facility Social Worker)

### **Getting to Know the Person**

Also noted in this study, was the finding that visiting and interacting professionally with the individual with TBI helps in getting to know the person and also helps in developing an initial rapport with him/her. The team understanding the individual’s background, needs, goals, and preferences helps to foster a better relationship, which in turn fosters mutual trust and respect. In this process, getting to know the individual was ongoing, as information was continually being sought and gathered throughout the transitioning process. Having an in-depth knowledge of the individual appeared to be a goal of the professional caregivers and community service providers, and they worked towards that throughout the process.

“...So, you know, so I have been trying to, ahmm, have those conversations in, and describing what the evaluation involves, that it’s just a lot of, ahmm, just getting to know the individual....” (Isadora, Occupational Therapist)

“Meeting the providers out at the facilities with them, to get to know them, to interview them, and things like that, with the guardians or health care proxies, etc.” (Antonia, DDS Service Coordinator)

“The second meeting, I usually will schedule right then and there. Most of the time the guardians don't come because it's more of me getting to know them.... I think what helps facilitate that is me getting to know them and becoming pretty, having a pretty good relationship with them.” (Cassandra, DDS Service Coordinator)

### **Developing Rapport**

As indicated earlier, both regular visits and getting to know more about the individual fosters the development of rapport, defined here as a natural feeling of mutual trust and respect among the individual with TBI and the professional caregiver. It is also worth noting that rapport is also developed simultaneously with facility staff through frequent visits and professional interactions. This is important as having strong rapport among the collaborative team promotes smooth transitions.

“When he first was meeting us, he was meeting with my dad to find out things my dad was interested in and trying to establish a rapport with my father...Oh, they did a good job with relationship building that's why my dad thought he was being adopted.” (Chossey, Family Caregiver)

“Yeah! So that's usually the first stage, you know.... really in building that rapport. The service coordinator has to build that relationship with the person. Because sometimes people with brain injuries, you know, if you're not visible and you're not maintaining that contact, then they might forget who you are since they have memory issues. So, it's really important to maintain that contact, build that relationship....” (Sue Smith, DDS Service Coordinator)

“The TCs are the ones that have built a relationship while working with them on housing, and core documents, and getting to know their needs, wants, preferences. That's their go-to person. So now, upon discharge, now the MRC caseworker takes the lead and our job essentially is done. However, the consumer calls us, they don't call MRC, they call us. They call the TC because they know Luz, they know ...our other TC's, that's who they call....” (Summer, Transition Coordinator)

## **Social Interaction**

Social interaction is defined as the way in which personalities, groups, or social systems act toward and mutually influence one another (Bardis, 1979). Findings in this study show that through social interactions between the individuals with TBI and their professional caregivers, community service providers, families, and peers, mutual relationships were fostered and built. Social interaction was mostly between the individual with TBI and staff at the residential group home. Interactions were also among the individual with TBI and his/her peers in the house, as well as their families. Through repeated daily interactions in the home, strong relationships developed. Even though social interactions were strongest in the residential homes, it occurred along the entire transition continuum. Professional caregivers, community service providers, and family caregivers helped in fostering these interactions through face to face visits, regular communication, and repeated social engagement through social outings and participation in organized social activities, including day programs.

“And then, you know, we bring him in, we'll have dinner with them and see how their communication and interaction goes. Hopefully, it's a smooth communication, smooth interaction... They do, they get along great, which is nice. Ahmm, so then...” (Caitlyn, Residential Program Director)

“.... So, like nobody really on his level that he could really interact with, so he did.... most of his interacting was with the workers, the CNAs and the staff, you know. It's not just three shifts of people, you know, and you get to know, you know. There's not such a turnover when it's in a house setting like this. Everything is more one on one, and you get to, you know, know each other and make friends more.” (Glinda, Family Caregiver)

“Because she just doesn't only interact with her son. She interacts with the rest of the gentlemen and you know, a couple of the gentlemen like sweets, so she'll bake. She'll come over there bring baked goods or bake for them and cook dinner for them, and stuff like that....” (Antonia, DDS Service Coordinator)

Within the process of relationship building, as depicted in Figure 17, social interaction occurred concurrently with the process of transition. However, along with the continuum and over time, such interactions increased. This increase was initiated from the meet and greet stage at pre-transition and nurtured through the transition phase to the post-transition phase. These phases will be elaborated further in Chapter 7. Social interaction was expected to be optimum at the post-transition phase, where full social engagement is encouraged and fostered by families, community service providers, and the professional caregivers.

“Ahmm, they help create relationships within the community, such as going to the same place, same time. Ahmm, whether it’s creating relationships, as in going for coffee with the same waitress all the time or going to bingo and meeting new people there and making friendships there, meeting a significant other at a club....” (Cassandra, DDS Service Coordinator)

“.... She tried the day program, it wasn’t for her, so I set her up with peer support. She and her peer go everywhere. They go to the beach together, they go to events together, they go to concerts together, etcetera, etcetera....” (Redsox, DDS Service Coordinator)

Through these processes, study participants described instances where strong relationships had been built post-transition to the community.

“Yeah! And all the people working here, that is my family.” (Dave, Individual with TBI)

“Oh, they’re buddies, they have favorite people and favorite nurses, whatever, who will bring them out for coffee or bring them out special treats.” (Chossey, Family Caregiver)

“I attend church with him, so I am very involved with him as well in the community and everybody there, and we became, really I mean...., we have become very close, yeah.” (Residential Home Staff)

“They provide, ahmm, the social aspect of things. The staff actually are, most providers staff interact and create relationships with these people that we, that are living in the homes.... Whether it is, you know, assigned to play games with them, getting out into the community, ahmm, going to see a movie, going to a concert, you’ll find that



some residents have preferred staff because they've built those types of relationships.” (Cassandra, DDS Service Coordinator)

“Yes! Yes. You know, we had a house manager, and there is a younger woman who we just transitioned to this home. I think she’s about—, she’s got to be maybe 31-32 years old. Anyways, the house manager, she’s close to 50. And the participant calls the house manager mom.” (Redsox, DDS Service Coordinator)

### **Summary**

In this chapter, a detailed description of the main processes of transition management has been described. The findings from this study, as reported, show that transition management can be complex, as it involves many different entities (the collaborative team), and many processes (communication, team collaboration, coordination, and relationship building). Even though these processes are presented here as distinct processes and may appear linear, transition management is interactive, and most of the processes are interconnected and may occur concurrently.

Furthermore, what the findings of this study show is that, central to all these management processes, was the core phenomenon of “it’s all about the person,” as described by participants throughout this study. The person (ITBI) was a key member of the collaborative team and was the expert to his/her care needs and preferences. During transition management, team members took their cues from the person in their decision making and actions, ensuring his/her needs were met and individual’s satisfaction attained, and relationships built.

Communication formed the backbone of all these processes and was the driver of the entire transition process. Communication between and across the inter-collaborative team fostered relationship building, team collaboration, and allowed for smooth

coordination of services, leading to positive transition outcomes. Team collaboration was also key to having a smooth process. Having a cohesive team engaged in shared decision making, shared goals, shared tasks, and understanding of roles among its team members were also described as important in transition management.

Establishing a relationship of mutual trust and respect with the person and among the team was a process requiring frequent and increased social interactions over time, leading to the formation of strongly built relationships and bonds. Having such strong relationships is vital, as it enhances a smooth transition process (see Chapter 8). A few more transition management processes, such as checking in, planning, and social engagement, will be discussed in the next chapter with the description of the transition process along a continuum.

## **CHAPTER 7**

### **THE TRANSITION PROCESS**

#### **Introduction**

Following the understanding of the core phenomenon that drives the transitioning process described in Chapter 5, as well as the transition management processes in Chapter 6, the next step is to give an explicit description of the transition process as it unfolds. As depicted in the “it’s all about the person” model of transitioning to the community, the transitioning of an individual with TBI from a long-term care facility is a complicated process that occurs along a continuum over time. The process goes through three identified stages: 1) a pre-transition (preparing to move) phase; 2) a transition (move to the community) phase and; 3) the post-transition phase (living in the community). These phases are distinct, but the change from the transition phase to the living in the community phase is subtle but defined by a distinct occurrence in the process, as will be described. The study does indicate that the timeline of this process is fluid and may vary as it is dependent on the availability of housing (residential group homes), and other factors. From the consensus of many study participants, it is noted that it takes at least a year to go through the pre-transition phase to the transition phase. The transition phase persists for up to about three months (or up until the day when a new individual's service plan is drawn, and new goals for the individual is set to mark the beginning of the individual's life in the community). The transition phase then continues into the post-

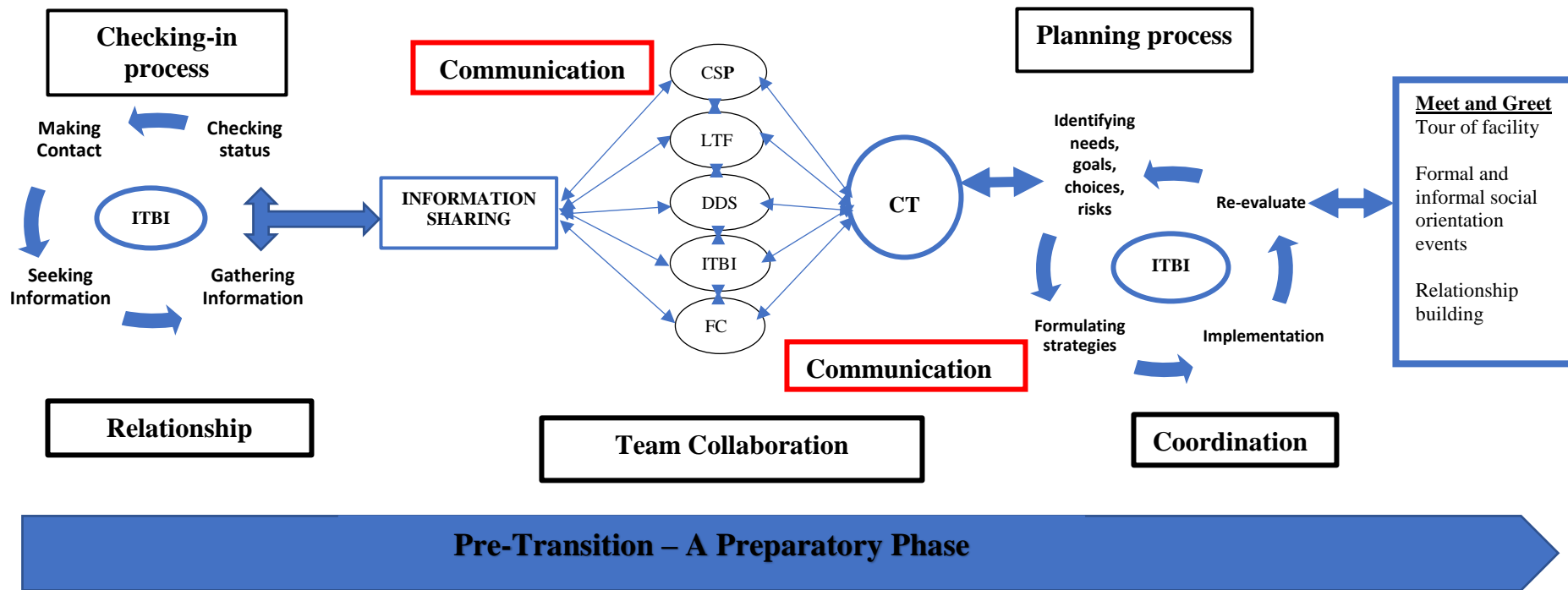
transition phase. In this chapter, each of the three phases and the process timeline will be presented in detail as described by study participants.

### **The Pre-Transition (Preparing to Move) Phase**

The transitioning of an individual with TBI from a long-term care facility to the community is started at the pre-transition phase, also referred to as the preparing to move phase. This phase occurs while the individual is residing at the long-term care facility. As the name suggests, it is a period of intense preparation. It is also a period where relationship building is initiated, as has been earlier described. This phase of preparation occurs in three processes: 1) the checking in process; 2) the planning process and; 3) the meet and greet, as shown in Figure 18. These processes are discussed as follows.

#### **Checking in Process**

The checking in process is the first stage of the pre-transition phase. This stage is an introductory stage where efforts are made to get to know the individual through making contacts, information seeking, information gathering, and information sharing through communication. It is also a stage where there is continuous checking in with the individual with TBI, their family, and long-term care staff. Checking in was done to receive updates on the clinical and psychosocial status of the individual with TBI; who has been made eligible to transition from the long-term care facility to the community under the ABI/MFP Medicaid waiver programs.



**KEY**

CSP: Community Service Providers

LTF: Long-Term Care Facility Team

DDS: DDS Service Coordinator and Team

ITBI: Individual with TBI

FC: Family Caregiver

CT: Collaborative Team

Figure 18: The pre-transition phase of transitioning.

## **Making Contact**

Once an individual is made eligible for the waiver program, an assigned service coordinator from DDS receives an information packet, and then initiates the transition process. The initial step in this process is to make contact with the long-term care facility through communication with the facility social worker, in order to schedule a face to face visit with the individual with TBI.

“If I—if a file comes to me for a person that needs to be transitioned from the nursing home to a group home, the first thing I do is that I contact the social worker at the nursing facility.” (Redsox, DDS Service Coordinator)

“So, with my team, initially when we get the participants assigned to our division in the metro region, my program manager and our clinical team, so whether that be nursing, psychology, our risk manager, will go out to the nursing facility and meet with the person.” (Jessica, DDS Service Coordinator)

Even though making contact was the first step in the process, it occurred many times throughout the different phases of the process when a new referral to a community service provider, for example, was made. In that instance, the contact person could be someone else, such as a residential manager at the group home.

“Then I go down and see the consumer [Individual with TBI]. I usually stop and see the social worker first and let her know that I'm there and why I'm there. And then I sit down with the consumer.” (Luz Marie, Transition Coordinator)

“Well, typically we would just get the call and then we would set the time with the nursing home to go and visit the individual that's being transitioned or in the idea of being transitioned.” (Joe Smith, Residential Program Director)

“So, once we get the referral, we make contact with either the, ahmm, supervisor or the group home or the individual home. If it's community-based, or group home- based, and we set up a time to come in and do an evaluation.” (Dee, Occupational Therapist)

### **Seeking Information**

Information seeking is the processes used when asking for information. At the visit, information about the individual is sought by interviewing the individual with TBI, if he/she can communicate. Also, the entities involved in the process interview the long-term care facility staff who were engaged in providing care to the individual. At this stage, interviews are mainly informal, and often conversational. Information is further sought by reviewing individual's medical records. Information is obtained about the person, their background, their preferences, their goals, needs, and their clinical status.

“We also, in that initial stage where they are first eligible.... we usually try to get some.... we do a lot of questions and a lot of history with them. So rather than just pulling from nursing facility records, we do an interview process.... ask them all types of questions about their likes or dislikes, where they'd like to live. What type of assistance do they think they need? What their goals are. You know, what they envision like living in the community, what they want to do....” (Sue Smith, DDS Service Coordinator)

They also seek specific information about their moods and behaviors. This was important to make decisions that ensured the safety of the individual, once he/she moved to the community.

“They'll ask a series of questions, they'll ask them.... if there're any behaviors. What are their tendencies? What are their likes, dislikes? Are there any precursors to behaviors? Are they a violent person? What triggers that? So, they look for all those triggers to create either behavior plans, if they're behavioral, or support plans if they have, ahmm, schizophrenia or what not, to help make their transition better and how the staff can support them once they transition.” (Cassandra, DDS Service Coordinator)

### **Gathering Information**

Gathering information was about obtaining the information necessary to make an informed decision to enhance the progress of the transition process. The process of

gathering information and seeking information could occur almost simultaneously, and one usually preceded the other. Though these two processes may appear similar, they differ. Information gathering involved collecting the information earlier sought; or it involved a physical act of obtaining information, usually through the professional's caregiver's assessments, which could be through observation or physical assessments. Gathering informational documents, such as copies of medical records, also occurred during this stage of the process.

“So, our evaluation includes, ahmm, an observation of the individual or client to see how their range of motion is, what limitations they have and what they wanna do, what they wanna participate in.... we look at like the whole range of everything from physical to mental to functional.” (Dee, Occupational Therapist)

“It includes all their preadmission documentation that we received from MassHealth, any PT/OT assessments that I can gather from the nursing home.....I try to get as much information as I can to provide to the provider...” (Cassandra, DDS Service Coordinator)

“I wanna know where am I going here? So, then we collect Ahmm all the core forms, personal forms like; birth certificate, social security card Ahmm, copies of course. Ahmm any income and how did they get their [injury]... It's much information because that will give me a good background and find out which way I have to turn with this consumer.” (Luz Marie, Transition Coordinators)

### **Checking Status**

The checking status stage of this process occurs later, usually about three months after initial contact. This process is necessary because actual transitions happen on an average of about a year after the initial contact with the individual. It is therefore prudent, to ensure that the clinical stability of the individual is maintained, or else the individual will have to go through a redetermination process for a possible denial to the program, despite his/her initial eligibility. Redetermination occurs when there is deterioration in the



individual's physical state such that he/she can no longer be safely served in the community setting. Therefore, professional service coordinators checked in periodically to monitor the status of the individual at the pre-transition stage in the process.

“You know, we go and meet with them on a quarterly basis. Every time we check in with the social worker; has there been any, you know, changes in status, has there been any, you know, increase in mobility or increase in their health status or decrease in health status, their hospitalization, what medications they are currently on. Things like that.” (Antonia, DDS Service Coordinator)

“Obviously we are continuing to go out and monitor the persons, you know, health and stability within the nursing facility, because that's always subject to change.... We're going out every two to three months to meet with them and if they are in hospice care or something big is happening we'll go out every month, and just kind of, you know, to make sure....” (Jessica, DDS Service Coordinator)

If the individual is found to have become more medically compromised, service coordinators check in on their status more frequently than the usual three months and have them under close surveillance.

“What we do is, for folks who are stable; we go out to the nursing facility and maintain contact with them every three months. If somebody's got a major health status change, we try to go out there at least once a month.... so that, you know, we can stay on top of what's happening because, you know, sometimes a situation could occur where someone might have a stage four wound, which could become septic, and they are in the hospital. And so, we are much more visible, and we increase our visits to once a month.... then as we go out there and we continue.... so, we've kind of had him on the radar that we go out to see him more often.” (Sue Smith, DDS Service Coordinator)

Checking status was not only about the individual's clinical condition. Under the waiver provisions, there are strict rules that have to be adhered to, in order to maintain eligibility. For example, an individual must keep a set amount of income to remain eligible for the program. Therefore, if one's income goes above the set limit, the individual is made ineligible for waiver services. Also, if the individual leaves the long-term care facility before his/her 90-day Medicaid stay, he /she is disqualified from the

program. Therefore, it was the responsibility of the professional caregivers to monitor their financial status and ensure that they remained in compliance with all waiver provisions.

“And for us, service coordinator, when somebody is accepted we usually follow up to the nursing home, what we do is.... three/ four months we go and check on their well-being and see if they’re still there, and try to stress on them that, you have to maintain your status. That means you can stay in any facility, but you cannot leave because, you know, once you leave before 90 days, they lose everything. So, we keep on stressing....” (Ubda, DDS Service Coordinator)

Throughout the checking-in process, information is sought and gathered. All the information obtained from the different stages of the process is shared through communication processes with and among the collaborative team, as has been earlier described in Chapter 6.

### **The Planning Process**

The next stage in the pre-transition phase is the planning process, and it is the phase where planning occurs at the macro level, with the involvement of the entire collaborative team. There are four main identified stages within the planning process, which include: 1) identifying the individual’s needs, goals, risks, and preferences; 2) formulating strategies; 3) implementation and; 4) re-evaluation. Planning at the macro level occurs in multiple transition meetings, which are organized and coordinated by the DDS service coordinators with the involvement of the collaborative team. Even though the planning process occurs predominantly in the pre-transition phase, it also happens at other stages of the process as well, and on a micro level within the different entities that make up the collaborative team.

### **Identifying Individual's Needs, Goals, Risks, Preferences.**

The initial stage of the planning process involves identifying the person's needs, goals, risks, and preferences. Most often this information is obtained at the checking in process. However, the team also collected new information during the transition meetings. Transition meetings are initiated towards the end of the pre-transition phase, about two to three months before the actual move to the community. The needs, goals, preferences/choice of the individuals are identified at the first transition meeting during this stage of the process, as described in Chapter 5. In this section, the procedures used by the professional caregivers, the community service providers, and families in identifying these personal elements during planning are reported.

“And then what we talk about at that first meeting is, we talk about equipment needs, supply needs, what do.... what does a person want regarding community providers? Is there a community provider network that they've had in the past that is close and do they want to use their old providers? Usually, it could be a yes, and the agency will say okay, and we'll set up appointments, you know....”  
(Antonia, DDS Service Coordinator)

The first transition meeting is just.... giving them a couple of pictures; letting them pick out their wall color. The transitional entity will be there to help, you know, organize and iron out what that person might want and reaching out to the nursing facility's social worker. And saying, well, these are all the specialized medical equipment.... make sure that incontinent briefs, you know, what kind of mattress do they need....an air mattress depending on how.... what stage wounds are, if they're at risk for that, what kind of medications.... we look at their medication.” (Jessica, DDS Service Coordinator)

“.... What the client or the individual needs as he moves towards home. You know, in terms of the rehab nursing home, they will tell us how much help they need, if they need one to one transfer. All those rehab things need to be supplied when they move home.... And the other area is to know the needs, that's why we have the medical equipment people ....” (Ubda, DDS Service Coordinator)

## **Formulating Strategies**

Formulating strategies was about the thought processes that individuals involved in the transition process engaged in when developing their service plan for the individual and the broader transition process. Formulating strategies is the second stage of the planning process. Once individual's needs, goals, risks, and preferences are identified, the professional caregivers, community service providers, and the rest of the collaborative team brainstorm to formulate strategies and develop a plan to meet these personal elements. For example, when the team identifies risks, such as the medical complexity of the individual, strategies are developed to mitigate them. Such a strategy could be finding a provider who can deliver a higher level of care in the community. During this stage of planning, tasks are identified and shared among individual entities of the team.

“We can kind of think and look outside the box and find that, you know, there's something out there that's adaptable, something out there that we can change to make it so that this client can do it....” (Elizabeth Hapgood, Rehabilitation Director)

“So, once we get the referral, we'll take a look at all of his past medical, we'll take a look at his behavioral aspects, anything that we might have a hard time with.... Supportive devices, things like that, and we kind of build a plan from there.... he'll start to formulate a plan in his head to be able to give him either the same services or better services within the home.... if they're having lung problems, a Pulmonologist, if it's a diabetic doctor, Jack (nurse) will kind of figure out what referrals he needs, what doctors he needs, and make sure we set those up. So, all that's kinda done before the transition....” (Caitlyn, Residential Program Director)

“Looking at their medical history, figuring out where and who we could best serve them with, and then it'll start with.... then that will be brought back to our team here.” Jessica indicated that there is a back process where they sit as a team, brainstorm, or formulate strategies. (Field Notes)

## **Implementation**

Implementation is about putting the thoughts generated into action. At this stage of the process, the ideas generated from the group think at the transition meeting are put into effect by members of the team. During the implementation, each team is expected to implement their shared tasks. For example, the long-term care facility may be given the responsibility to ensure that durable medical equipment is ordered and obtained before the transition. They implement their tasks by coordinating with members of the collaborative team, as well as outside vendors, through communication and by sending referrals. In this study, participants described the implementation process as it occurs during the planning process.

“We talk about it in the formal like.... with the director of my company, the psych director.... the first transition meeting that we have, we talk about all those things ...but then we actually make it happen at floor level.” (Caitlyn, Residential Program Director)

“.... There needs to be a VNA referral for PT, OT, if there's any skilled nursing that needs to happen, that all needs to be put into place. Hospital beds, if there needs to be a hospital bed that needs to be ordered.... Ahmm, I try to make sure that incontinent supplies.... They already have the PCP in the facility sending over the letter of medical necessity and the script for incontinent supplies, so this way it's already through that process. And the delivery of those supplies happens on day one when the person moves.... Provider has to provide transportation for the person to get home with all their belongings from the nursing home, so they have to make those plans and those arrangements. The provider hires staff and also ensures that they are trained on that person specifically before they transition.” (Cassandra, DDS Service Coordinator)

The implementation process is also about the person. The individual is made part of the decision making and continues to make choices, even at this stage of the process.

“We have to have a doctor's appointment for them at least 30 days from the time they move in, so a lot of times we have to pick the doctor at first and then make the appointment, if they don't already have a doctor. But if the individual doesn't like that doctor or they're not comfortable, then we switch; we'll find them another one.” (Joe Smith, Residential Program Director)

Implementation is a critical stage in the process. The service coordinators hold off transition if the implementation process fails and essential needs are not in place at the time of the final move to the community. Therefore, multiple transition meetings are held to re-evaluate, plan, formulate new strategies, and then attempt to implement the new transition plan. This re-evaluation process is done to minimize or prevent failed transition attempts. The re-evaluation stage of the planning process is discussed in detail in the following section.

“Ahmm, I have stopped transition because it was an unsafe discharge with nursing homes because they failed to get the equipment or get a wheelchair to send them home in and they were not willing to give a loaner. So, we had.... they had to figure something out....” (Cassandra, DDS Service Coordinator)

“Let’s say, for example, a shower chair wasn’t delivered. Then we can’t discharge, because this person has to take a shower safely. So, all that equipment I try to check two or three days before discharge.... no, we’re not going to discharge, especially if it’s something important.” (Redsox, DDS Service Coordinator)

### **Re-Evaluation**

Re-evaluation is the final stage of the planning process, and it occurs at the second and third transition meetings before discharge. It is the stage of the planning process where the collaborative team sits to re-evaluate their plans of action and to rectify any problems that may have arisen during the implementation phase. During this phase, members of the collaborative team report on the progress of their task and any difficulties encountered. For example, there may be a problem with the individual’s insurance or a request to buy some equipment may be denied. During this phase, new strategies will be put in place to obtain the equipment. Sometimes funds from the waiver program are utilized to solve such problems, as was described by study participants.

“The second meeting, you know, happens maybe two to three weeks later. And at that point, we like to touch base with the nursing facility, social worker, to see what’s been denied by Mass Health because that is a great indicator if there are any red flags that we might need to deal with before they move in.... So, then I can turn around and utilize the waiver to purchase things like bed rails or, you know, Hoyer lifts and slings, ostomy supplies. And then to really iron out the medication at that point too, and to make sure the transition is going to move smoothly.... after the second transition meeting, if it’s necessary that we have a third one, we will ....” (Jessica, DDS Service Coordinator)

“.... we have a second transition meeting .... So, we make sure that, like, the provider agency has all the prescriptions from the doctors at the nursing facilities.... all the little last-minute things that we need to put into place, we make sure we have.... if they need any hospital beds that, you know, we'll get those there the day of delivery. It's a lot of behind the scenes planning the last a couple of weeks, and just making sure all of our "I"s are dotted our "T"s crossed (Antonia, DDS Service Coordinator)

“So, the second meeting, we talk about the progress on anything, if there have been any hang-ups with insurance or anything like that.... and at the 3rd and last meeting, which is probably about a month before they move, just kinda wrapping everything up and making sure that the house has been in contact .... with the facilities.” (Sue White, DDS Service Coordinator)

### **Meet and Greet**

Meet and greet is the final stage of the pre-transition phase and it occurs a week or two before the actual move to the community. During this phase of the process, efforts are made by professional caregivers and community service providers to orient the individual with TBI and the family to the new home. They give a tour of the new house to the individual with TBI and the family, and information on the rules of the house are shared. In addition, formal and informal social events are organized, such as dinners and social outings, to foster relationship building among all the new occupants, their families, and the staff in the home. Meet and greet, as indicated earlier, is often the first social interaction that occurs with the individual during the transition to the community.

“.... Once the construction is done, and we’ve just decorated part of the common areas, they will come and do a home visit. And then, prior to moving in or opening up a new home, we’ll have the four individuals.... will meet again at the same time at the home, so they get to meet each other as well.” (Joe Smith, Residential Program Director)

“We all met here a couple of months after that.... meet and greet the families and see if we thought that would work out, it's been fine ever since then.... I think it was in the meeting with the whole families here when they went over the rules, like no alcohol, ahmm, and it's a whole patients' rights thing...” (Chossey, Family Caregiver)

“Some providers will schedule a dinner, cookout, depending on the season, for all the individuals and their families to meet. Some providers are better than others with it, but I try to encourage that as much as possible.” (Cassandra, DDS Service Coordinator)

Usually, providers organize one meet and greet event. However, in a few instances they will do multiple events to foster more relationship building.

“The provider agency will set up a meet and greet, open house night, so that everybody who’s going to be living in the home can meet each other and have a meal together. Some agencies do two of these, some agencies just do one....and they also bring in whomever else is a part of that person’s internal.... intimate circle, whether that’s friends or family. From there it’s just probably a week or two.... maybe less than a week until they transition into the home.” (Jessica, DDS Service Coordinator)

At this stage of the process, the individual with TBI becomes hopeful and emotional, as they realize that the day of the move is getting closer and they are going to be leaving the long-term care facility after having been there for many years.

“And he's become disillusioned because, he's like, I've been waiting so long, I've been waiting so long, I've been waiting so long. But now he is at the point where we are at the second transition meeting; he sees it as it's really happening and we're scheduling him to have a tour of the home and have lunch and meet his roommates. He was just about in tears. He couldn't believe this is actually happening.” (Sue Smith, DDS Service Coordinator)



### The Transition (The Move to Community) Phase

The Transition, or move to community phase, is the second phase of the transitioning process where the individual with TBI is moved out of a long-term care facility to a residential group home in the community. Before I proceed to describe the actual move to community process further, I will give a brief description of these residential group homes to help the reader fully understand what this move may mean to the individuals with TBI, their families, the professional care caregivers, and community service providers.

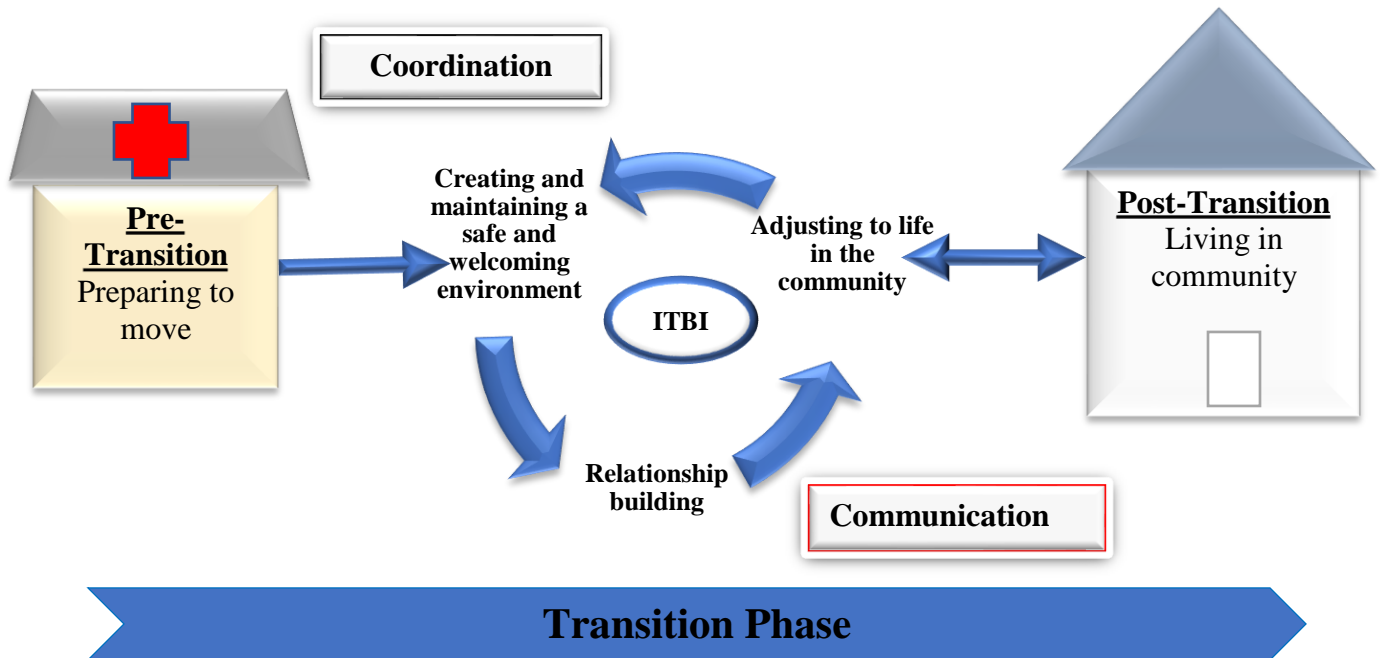


Figure 19: Showing the transition (move to community) phase of the process.

### **A Residential Group Home**

A residential group home is a waiver approved home that allows no more than four ABI or MFP waiver approved participants to reside in the home. These homes are privately owned by contracted state providers and regulated by the Commonwealth of

Massachusetts. They are usually built brand new from the ground up, or they are newly renovated houses. Pictures on next page show a model group home.

“And they identified a plot of land in Hudson which is just really on the edge of the metro area, and it's going to, it's being built from the ground up. It's going to be absolutely beautiful. We have these other providers who are still trying, they're in the process of trying, to find either a house to rehab or land that they can purchase so they can build the home, you know, specifically towards the specifications that we need for.... to accommodate folks with acquired brain injury.” (Sue Smith, DDS Service Coordinator)



Figure 20: A picture showing layout and amenities within the residential group home.

These homes have been described as beautiful, accessible, and expensive houses by study participants.

“Ahmm, and you know, when you look at how much money is.... that that's costing. These homes are three-quarter of a million dollars to a million and a half to build. So, these are, they're very nice homes, very nice homes.” (Chip, DDS Service Coordinator)

“She loved the homes and described them as beautiful.” (Field Notes)

“The house was just so gorgeous. I was like, I want to live here, look at this kitchen. So, he was excited about it....” (Nicole, Facility Social Worker)

The transition phase starts at the day of move in and up until about two to three months in the community. It is a time when a service coordinator from DDS comes in to sit with the individual and draw a new individual service plan with them. This phase is also a time when the individual is perceived to have become somewhat familiar with his/her new environment. The transition phase is characterized by three processes, as depicted in Figure 19, and as follows: 1) Creating and maintaining a safe and welcoming environment; 2) Relationship building and; 3) Adjusting to life in the community. These processes, except relationship building, will be described further in this section, as relationship building has been elaborated upon in Chapter 6. The transition phase starts at the day of move in and continues until two to three months in the community have passed, a time when a service coordinator from DDS visits the individual with TBI and develop a new individual service plan focused on living in the community. This phase is also a time when the individual is perceived to have become somewhat familiar with his/her new environment.

### **Creating and Maintaining a Safe and Welcoming Environment**

Before the move, residential group home staff coordinate through communication to confirm that their team is ready to receive a new client. They hold meetings to ensure that they are all on the same page about what the individual will need once he/she gets to the home. They physically confirm that the individual's room is set up and ready for them when they move to the house. A welcoming environment is created for the person. Rooms are personalized and decorated so that the individual may feel at home and have a personal connection to the space.



Figure 21: Showing a room setup within the residential group home.

“Yeah because Kennedy came up with the idea of having some pictures or something they can connect to, like sports, flowers.... something they like.... hobbies. So, if somebody likes the Red Sox or any type of sports, Kennedy made sure that she had something in their bedroom or living room, something....” (Luz Marie, Transition Coordinator)

“So, usually before we transition someone in we have a staff meeting, so we have all of our staff on the same page that, you know, we'll have a staff meeting in the morning saying, alright, Carl is coming on Thursday, what do we need to get ready? Ahmm, so, we picked out Carl's furniture. Carl's furniture didn't get delivered by the time he got transitioned in, so we had to make things happen really quick. So, ahmm, we ended up using a hospital bed that we had on hand, cleaned it up, made it his...” (Caitlyn, Residential Program Director)

On the day of the move to the community, staff from the residential group homes, or the family, physically go to the facility with transportation to discharge the individual from the long-term care facility to the community. During discharge, they make sure the individual has their medications, new prescriptions, and their personal belongings with them.

“The day they move that's.... what happens that day. Usually, the provider agency will go pick them up from the nursing facility, or maybe the family will, you know, move them out of the nursing facility and drop them there. It could be either....” (Antonia, DDS Service Coordinator)

“Some consumers are by themselves, or their family cannot make it. So, our driver .... does an unbelievable job. He gets very involved with the consumers, you know, assisting, because we could show up at the nursing home and they say, oh I only have two boxes; we made three trips one day.... and we're not movers. When you show up thinking it's only two boxes, and they come up with like ten boxes....one had a bicycle [laughs] ...” (Luz Marie, Transition Coordinator)

From the initial acceptance to the waiver program to this phase takes about a year plus. Therefore, due to the long wait, the individual may sometimes lose hope or become disillusioned with the process. Thus, the day of move in is an emotional day for the individual and professional caregivers, and there are mixed feelings of excitement and anxiety on the part of the individual with TBI.

“I was excited; I said what kind of place I come (expresses surprise). It was a nice house; it is a place somebody lives, you know.... I am glad I came here.... I see my room; I say is this for me? I am so happy to stay here.” (Dave, Individual with TBI)

“Very, very excited, very anxious, ahmm, and it's funny, not the anxious.... it's not anxiety because they are leaving familiarity and they're leaving what they known for years or years, however long. It's the.... it's more of, ahmm, like someone who just bought a home or someone who just got their first apartment....” (Rickie, Facility Social Worker)

And there is a sense of fulfillment for the professional caregivers who have worked so hard to get them to physically move out of the nursing facility.

“It gives me like a warm and bubbly feeling on the inside because, you're like, this is why I do the work that I do. Because talking about all this stuff when they are getting ready to move, just seeing their faces and their reaction and their excitement .... Some people have been in nursing facilities for ten years, five years, two years. So, like, I always get that feeling and....to watch clients on the day of moving, we as service coordinators, we always go out there...” (Antonia, DDS Service Coordinator)

“This is what makes it all worthwhile, this is, you just, you just.... want to break down in tears because you just can't believe this is.... you're so happy for them...” (Sue Smith, DDS Service Coordinator)

Upon their arrival at the house, efforts are made to create a welcoming and safe environment for the individual. There is interaction between staff and the individual with TBI, as they start to build relationships. The residential home staff makes an effort to help them feel comfortable and welcome in the home. They help them settle in by assisting them to unpack and decorate their rooms (putting up family pictures, etc.).

“We brought him right into the room.... One of the things we did is we made sure that Carl brought anything from the nursing home that he wanted. So, he had this one blanket.... the first thing I did was I went to his room, put on his blanket when he was getting adjusted and bringing stuff in. I put his blanket in his room to make sure it was on his bed, hung a couple things up for him that was personal to him to make him feel like it was home.” (Caitlyn, Residential Program Director)

“What we usually do is we let them get settled into their new home, get decorated if they want to, get to meet their staff... it's a great day.” (Antonia, DDS Service Coordinator)

“Oh yeah, yeah, I remember them, some special person came over to help decorate their rooms with them.” (Chossey, Family Caregiver)

“They'll paint the color of the room that person's favorite color.... they will ask, you know, are you a morning person, are you an early-waker or are you a late-waker? Are there times during the day that you don't want to be bothered? You know what I mean? So, these are very important individual questions to get to know the person and, like I said, 98% of our providers do a very good job.... very good job.” (Redsox, DDS Service Coordinator)

During the first day at the residential home, the emphasis is placed on ensuring the safety of the individual. The management at the residential group home organizes fire drills with the individual with TBI and their staff.

“Also, someone from our quality assurance department goes out, and they run the fire drills to make sure they can evacuate in the 2.5 minutes. So, every time someone moves in, that person from our OQE department goes out and runs the fire drill. So, if the, if its 4 different people moving in on four different days, they

have to go those four different days and so do we, you know.” (Antonia, DDS Service Coordinator)

### **Adjusting to Life in the Community**

Adjusting to life in the community is the third stage of the transition phase. Once an individual with TBI moves into a new environment, he or she goes through a period of adjustment. These adjustments can be psychological and physical. The individual learns to get used to all the new changes he may be experiencing, including new-found freedoms. For example, he may have a new primary care physician and new staff at the home that he may have to get to know and get used to. He also must get used to the rules of the home and learn how to navigate around in the new house. For an individual with a brain injury, these changes can be overwhelming, and adjustment takes time. Adjusting to life in the community is more prominent during the initial move at the transition phase of the process but may sometimes persist into the living in the community phase. During their first weeks at the house, some may work with a therapist to help them get through this period.

“Yeah, to adjust to the place and for the staffing team to get to know them, switch of the doctors, now the primary care doctor. So, this whole package, which takes some time to kind of adjust, but also for them probably just to adjust themselves to the new setting. But they’ve done a lot.... there is an improvement.... they’re getting better; it took them some time to get to figure that....to get the trust, to feel this homey environment, this is where we belong.” (Ubda, DDS Service Coordinator)

“It’s not necessarily, they don’t like it, but it’s a change. And when you change somebody’s environment, especially somebody with a TBI, it can be scary. Not that a lot of them will admit it.... And its adjustments. It’s an adjustment for them.... So, they typically will see a psychiatrist once every three months. But they’ll see a therapist typically, in the beginning, it’s once a week.... And they come up with good strategies to help us work with the individuals, as well. So, we

work pretty closely with the therapists.” (Joe Smith, Residential Program Director)

Adjusting to life in the community is very much dependent on the individual and the period of full adjustment varied from person to person. This phenomenon was reiterated when one residential home manager was asked what the time frame was for the individual to get adjusted after their initial move to the home.

“I don't think there is an actual time frame for that. Everybody is different. With Carl, it was right away; another individual.... ahmm, another individual, he's still working on it, so I think it's all an individual kinda case.... We do everything to make them feel comfortable, but I don't think you can put a time frame on that.” (Caitlyn, Residential Program Director)

However, the residential group home staff and service coordinators work hard during this phase to ensure that happens. In this study, participants described some of the processes they engaged in to ensure that adjustment is achieved.

“.... he has a cabinet, you know, that's his cabinet, only for him. It makes him feel good. Because he knows that's his food; that he picked out, that nobody else really touches. It gives them a sense of being independent, of being accepted into the home and it really did help him adjust and be very comfortable.” (Caitlyn, Residential Program Director)

“Being able to adjust smoothly. There is always going to be some sort of hiccup along the line anyway, but the staff in itself are trained in a specific way that we don't go in and just do direct care, or whatever. Staff are trained to walk in and go, what can I do for you? Not, here we are, this is what we're doing...it's giving the individuals that are moving in here control... that they've never had for a while....” (Joe Smith, Residential Program Director)

### **The Post-Transition (Living in the Community) Phase**

The post-transition phase is the final phase of the transitioning process. At this time in the process, the individual has successfully transitioned out of the long-term care facility, and he/she is living in in the community with many supports and services. This



phase is mainly about fostering normal aspects of life in the community, as shown in Figure 22 below.

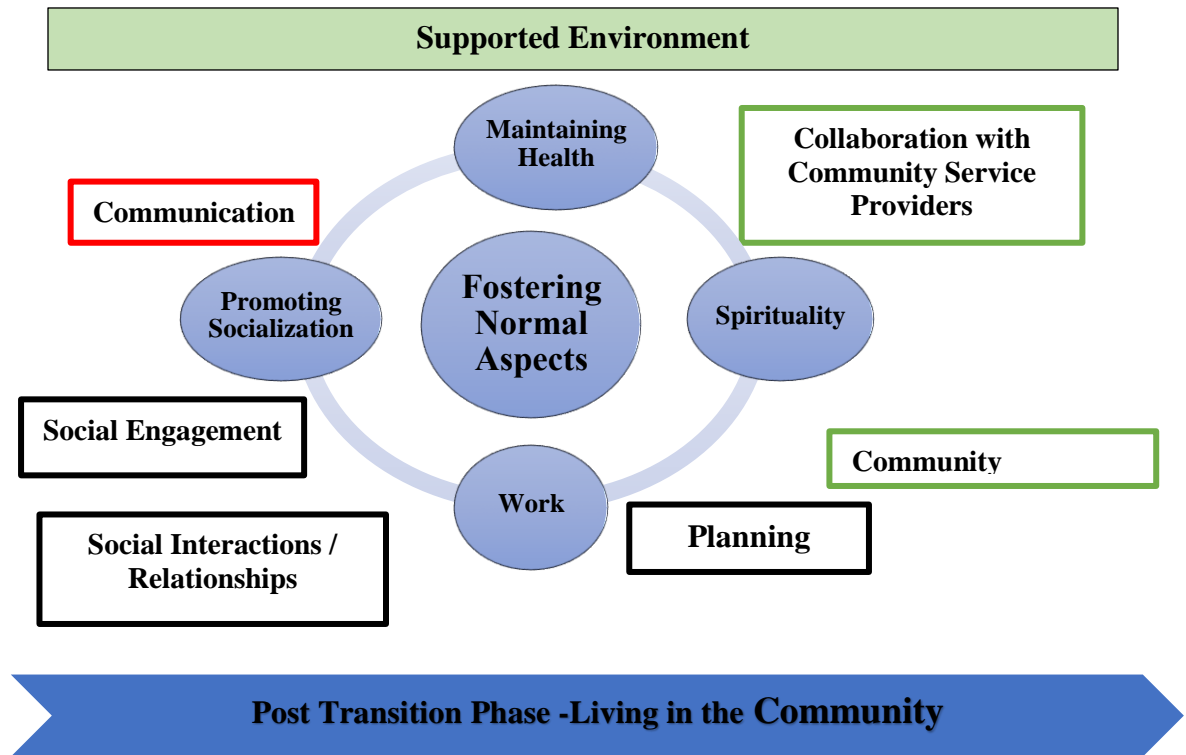


Figure 22: Showing the post-transition phase of the transitioning process.

### Fostering Normal Aspects of Life

Fostering routine aspects of life is achieved with close collaboration among the team and with community service providers including visiting nursing agencies. Communication, planning, relationship building, and social engagement are key management strategies used here. The community services and supports available at this phase of the process helps the individual be successful in achieving life goals.

The areas where community service providers and professional caregivers focused when fostering normal aspects of the life of the individual with TBI and their

families included: maintaining health, promoting socialization, work, and spirituality of the individual with TBI. In this study, the processes used in fostering the routine aspects of life for the individual with TBI from their perspective and the perspective of the family caregivers, the professional caregivers, and the community service providers, is described.

### **Maintaining Health**

Individuals with TBI living in long-term care facilities, tend to have significant cognitive issues and physical disability due to the injuries sustained as a result of their trauma. Many of these individuals have chronic medical needs and maintaining stable health is a priority during this process. Professional caregivers, family caregivers, and community service providers described the processes they use in maintaining the health of the individual with TBI. Some of these included: providing direct care, promoting continuity of care, providing education, and promoting independence through rehabilitation as shown in Figure 23.

### **Providing Direct Care**

In the residential group home setting, staff provides direct care to the individual with TBI. Direct care includes helping with activities of daily living such as bathing, grooming dressing, eating, toileting, transfers and incontinence management. They also assist the individuals with instrumental activities of daily living, which include cleaning and maintaining the house, managing money, preparing meals, helping with their grocery

shopping, and other necessities. They also assist them with taking their prescribed medications and the residential homes ensure that their staff is MAP certified.



Figure 23: Maintaining the health of the individual with TBI during transitioning to the community.

“So, we administer all their meds, we are all MAP protocol safe, so our medication administration program is what we use for our MAP. So yes, my nurse will go in, and he'll transition all his meds from the facility we'll make sure his med sheets are all appropriate.” (Caitlyn, Residential Program Director)

“Ahmm, no not all of our staff at the house but the majority of the staff. There is always somebody here who is a med certified staff. You have to be a med certified staff to be able to give meds.” (Staff at the Group Residence)

“They give me my medicine everyday.... Yeah and the foot, and they wash my back and the rest is me.” (Dave, Individual with TBI)

“He...some...right now he's declining, so he needs help transferring but he used to be able to transfer himself into the bathroom, but he needs a lot of coaxing because he has no will to get in the shower at all.” (Chossey, Family Caregiver)

“They help with financial management, ADL care, ahmm, community integration, ahmm, medication administration, getting them to the doctor's appointments

easily, not having to worry about whether or not they're...where their next meal is coming from.” (Cassandra, DDS Service Coordinator)

Most of the residential group homes do not offer 24 hours a day, 7 days a week nursing services, and therefore are limited in the nursing services they can provide. Individuals that need skilled nursing care are supported by an identified visiting nurse agency that provides services such as diabetes management, wound care, and intravenous (IV) therapies.

“If they have an extensive medical need and the home cannot provide nursing. A lot of times group homes will have nursing that is oversight nurse, meaning that they’re not a fulltime nurse within that program. They oversee multiple programs. We currently have just been allotted nursing into this program, because we have an individual that is a diabetic, gets insulin. We weren’t able to take him at first, because we didn’t have nursing. So those are some of the things that....” (Joe Smith, Residential Program Director)

However, a few homes do provide 24/7 nursing services and take on medically complex patients with gastrostomy tubes for feeding and tracheostomy tubes for breathing, among others.

“It’s a medical complex house. They have the tube, the trach; they have oxygen at night and an LPN. The house is supposed to have an LPN all the time for suction and everything.” (Ubda, DDS Service Coordinator)

### **Promoting Continuity of Care**

During the transition of the individual from the health care setting to the community, professional caregivers and community service providers ensure that there is a continuity of care as they transition the individual with TBI from the long-term care facility to home.

“They’ll have to have a physical exam within the first what, two weeks of them moving, so the provider nursing team will usually set that up before they even transition out of the nursing home ... If they don’t have a specialist in the

community, we have their new PCP refer them to.... If they need a cardiologist or a neurologist some of them already have the providers.... And if we can use the old providers like the neurologist, the cardiologist or whatever specialty, the endocrinologist we will use those, but if not, we'll look for another new specialist in the community .... closest to their home if that's what they want...." (Antonia, DDS Service Coordinator)

".....Everybody goes for follow-up PCP appointment, as soon as they are out to make sure that all their meds are in order." (Rudy, DDS Service Coordinator)

"Let's say that's the area we usually try to make sure in terms of the continuation of services. One of the things we do in transition meeting is to make sure the provider will be able to get the doctors.... you know, primary care doctor if somebody has other psych issues, we make sure we have the psychiatrist appointment in place, so somebody can follow them and continue to do, regarding medication, medical evaluation and everything." (Ubda, DDS Service Coordinator)

### **Providing Education**

In maintaining the health of the individual with TBI, staff and professional caregivers offer education on making healthy and safe choices. For example, teaching on sexuality is encouraged at the homes since many of the individuals are young men that express sexual needs. Therefore, the staff is trained to help educate them on safe and smart sex.

"So, in that aspect, they do have their privacy, and they have a lot of their privacy, if they wanted to foster and build a relationship with somebody. Ahmm, we could definitely help them understand that we could support them and give them counseling. We could support them in giving them, you know, education on safety, safe sex education, smart sex education." (Caitlyn, Residential Program Director)

"Ahmm, they have a lot of support centered around, ahmm, being intimate and learning appropriateness (laughter).... whatever it means for that person. And providing support and education around that.... group homes are putting their efforts into training their staff, providing that education, giving them guidelines of what they can do how, they can approach it, things like that." (Cassandra, DDS Service Coordinator)

### **Promoting Independence Through Rehabilitation**

Promoting independence was a key focus of both professional caregivers and community service providers in maintaining the health of the individual with TBI, once they transitioned to the community. Independence was promoted by encouraging participation in rehabilitation while living in the community. Rehabilitation services were provided in the home through the waiver approved community-based service providers or at their day programs. The rehabilitation services available included speech therapy, occupational therapy, and physical therapy. Staff at the group home provided oversight and ensured that their treatment plans were being followed. They also encouraged the individual with TBI to take an active part in their care to further promote their independence.

“It’s also trying to figure out with the staff how they can be more, ahmm, how they can be safer. But how they can be a little bit more independent, even if it’s something as simple as rolling in the bed to help out with, you know dressing, versus them not being able to dress. Ahmm, so I have worked a lot with the different staff trying to get them (the individual with TBI), you know, to be safer and more independent.” (Alyssa, Facility Social Worker)

“Our philosophy in the programs that I open is, we do with and not for. So, we want to challenge them to do as much as they possibly can for themselves.... if they can, if they can, even if it’s just one arm. It doesn’t matter, as long as they can do something for themselves. It just builds self-esteem. We have one individual that.... he just recently now has been able to access public transportation independently, which he didn’t do before coming here....” (Joe Smith, Residential Program Director)

“She is now self-medicating; she can do her meds by herself now. Every single three months, she becomes more and more independent.” (Redsox, DDS Service Coordinator)

## **Promoting Socialization**

Socialization is one of the aspects of life that professional caregivers, community service providers, and families support when the individual with TBI is in the community. Socialization in this process was about encouraging social interactions and social engagement or community participation. Earlier in Chapter 6, social interactions were discussed in the context of relationship building. The focus in this section will be on social engagement and the social activities that the individual with TBI participates in during socialization with others and the community at large.

### **Social Engagement**

The individuals with TBI in this study experienced social isolation when they lived in the long-term care facility, as they lacked peers their age. Therefore, increasing social engagement is a shared goal among all involved in the transitioning process, including the individual with TBI, their families, professional caregivers, and community service providers. Throughout this study, they described instances where social engagement of the individual had been a focus. The DDS service coordinators described their processes, where they made efforts to incorporate the individual's social interests into the individual service plan (ISP) as a goal. The ISP is regarded as a legal document, and the residential home staff are bound by it and are expected to help the individual meet those goals and engage in the community.

“When I’m doing the service plan with the person, and we’re coming up with the goals.... So, I try to throw questions in there to try to steer the person to give me ideas on social events, social things that they enjoy doing. One person.... wanted to go to romantic Latin music concerts. Well, if I don’t put it in the service plan, then it might not get done, but if I put it in service plan as a goal, it kind of puts pressure on the provider to do it.” (Redsox, DDS Service Coordinator)

“As far as, ahmm activities and making sure that they are trying to get out and doing these activities in the community, they use a social calendar, networking plans.... They'll make sure that they have house meetings to talk about what they're going to do as a house, but also what the individual is going to do on their own..... If it's something they're interested in or have relationships that they want to be fostered, we make sure it's put into their ISP so when it's written in their ISP.... it's a legal document, and they have to ensure these services are done. If it's not .... they're not bound to make it happen.” (Chip, DDS Service Coordinator)

The service coordinators work very closely with the residential group home providers to ensure that the individual participates in social activities and that he/she is engaged with the community.

“So, someone may like the music, want to go to a concert maybe.... summer time, maybe two or three times. We try to work with the provider to make sure this happens as much as they can.” (Ubda, DDS Service Coordinator)

“You know, sometimes you have to help the provider along too. Like, for instance, the beach trip. Oh no, this person is in a wheelchair. And? How am I going to get him to the beach? Well, there is a beach in Connecticut that's completely handicap accessible. So, you can bring the person into the water. The person hasn't been in the water for 20 years because they've been in the wheelchair. This is an opportunity for them to go to the beach and experience something they haven't experienced in a long time. So, I try to do things like that.” (Redsox, DDS Service Coordinator)

The residential providers also work hard to foster social engagement, planning for that and providing the necessary resources to make it happen.

“If I need to have three staff on, then I have three staff on.... if I have an individual that is one going off who wants to go apple picking and another one that wants to go to the movies, we do weekly calendars with the individuals. A staff person will sit with each individual separately and go over the weekly calendar to plan what they want to do. So, we know a week in advance what we need to schedule and plan. So, I will staff it accordingly.” (Joe Smith, Residential Program Director)

Social engagement is also achieved by spending time with family, and friends which was also encouraged at the residential group homes.



“Saturday, I went to one place in Fall River for a party.... On Christmas day, I don’t stay here. I go to my brother in law’s house because all the family is there.... After I eat, I drink espresso and talk and play with the people, friends there, and the family there.” (Dave, Individual with TBI)

“The good side is that if he wants to go somewhere they're right there to take him. We asked if he could come up last Friday and they brought him right up.” (Mary, Family Caregiver)

“A lot of times.... like we have one individual who will go this Saturday to his niece’s house, and she is having an outdoor party. He would not be able to get into the house, physically, but they can visit outside. So, we’ll have staff take them to go and visit there. Some do have husbands or wives, and if they choose to come here, they can do that as well.” (Joe Smith, Residential Program Director)

### **Social Activities**

Individuals with TBI were encouraged to engage in many different social activities at the home and in the community. The individual's choice was always respected when it came to the type of social activities they engaged in. These activities varied and included going to the beach in summer, going to movies, going to concerts and religious shows, watching their favorite TV shows, attending day programs, going to the library, going shopping, attending organizational parties, spending time on social media, among others.

“I said, I know that they have likes.... they do birthday parties and, like, they'll, they’ll have Halloween parties.” (Glinda, Family Caregiver)

“In the summer there are cookouts between this house and other house. They have outings, they go out to lunch, a couple times a week they can go, they go shopping, and they have a Christmas party every year. They said your dad is interested in seeing an MA, MMA fight.... we’ll take them to Foxwoods or wherever the fight was and stay overnight with a staff member and let him see the fight.... he totally did that. He really enjoyed that. Like, they really go above and beyond to provide enriching activities.” (Chossey, Family Caregiver)

“We will have throughout the holidays, depending on their religion, we’ll have specific events.” (Joe Smith, Residential Program Director)

“He has a Wii game that he plays, he is able to do that, the Wii. I put him on Facebook; I got him a computer. I had him playing zombies and, oh my God, every time a zombie blew up we'd crack up you know, and then he played Candy Crush. He loved Candy Crush because it was repetitious, you know.” (Mary, Family Caregiver)

“They go to the beach together; they go to events together; they go to concerts together etcetera.... She wanted a garden; she takes care of the garden. Sometimes I see her, and she is all dirty from the garden, and she does her tomatoes and everything.” (Redsox, DDS Service Provider)

“So, they'll go out. Yeah, they'll go out in the evenings too. We'll bring them to Boston Bruins, ahmm, Providence Bruins games. We're doing LaSalette this Sunday....” (Caitlyn, Residential Program Director)

## **Work**

Individuals with TBI who transition to the community have some disability and are unable to go back to full employment. However, to foster the normal aspects of their lives, they are encouraged to do some activities in the community and to keep busy. Engaging in such activities is considered work, like going to day programs, volunteering, etc. Many waiver-approved day programs provide opportunities to these individuals to do some minor tasks to keep them busy. Others also engage in supported employment where they can work part-time either on a farm to collect eggs or do volunteer activities to keep them busy. This gives them confidence and enhances their self-esteem. Study participants described how they foster the individual's return to work.

“We have just one individual that does do a day program Ahmm; he goes down to supportive employment where he actually works a few hours a week. It makes him feel good about himself and gets him some extra money, and if he needs support, there's an RN down at that program, so there is nursing available at all times down there too.” (Caitlyn, Residential Program Director)

“Oh yeah, but they were offered other things to do in place of work. Like a therapy and day programs and stuff like that.” (Chossey, Family Caregiver)

“They get training. Some supported employment will provide a job coach. I have two individuals right now who are doing supported employment....at a farm. One guy, all he does is just count eggs. That’s his job. He counts the eggs. But they pay him. Pay him minimum wage alright and he works anywhere between 15 to 20 hours a week, and he loves it. The supported employment will work with the person and meet the person where they’re at.... or whatever modifications need to be made.” (Redsox, DDS Service Coordinator)

“And also, we use other providers like job.... like vocation that I can call, if they don’t want to do volunteer forever, they want to do something different.... At MRC, right now what we’re doing is, we have something they call.... outreach, So, one of my individuals, she tries to prepare the videos and everything and she is ready to go back there [nursing home] and talk and just have something to do for the day.” (Ubda, DDS Service Coordinator)

Despite the encouragement to go back to work, under the waiver provisions, the individual may not earn more than \$2000 a month, as it will put them out of compliance with the waiver regulations.

“I also try to explain to the person from the beginning to not agree to work more than 40 hours a week, because that can mess up your whole—your social security benefits, etcetera, etcetera, because you’re not supposed to make more than \$2000 a month. Alright, if you make more than \$2000 month that may affect your benefits, so I explain everything from the beginning, if that’s an avenue that they would like to take.” (Redsox, DDS Service Coordinator)

### **Spirituality**

The individual’s spirituality is also fostered and encouraged while living in the community. Individuals are supported to express and live their faith. They are allowed to have any religious artifact if they choose to, and they are also encouraged to attend church services or other religious services if they opt to do so. Staff accompanies them to their religious services. One participant explained how he goes to church every Sunday

with one of the staff members. In doing so, they have formed a close bond, and during my observation and interview sessions, he will revert to her for guidance or cues.

“So, then we put the pictures in a photo frame and got them in his room, hung up his pictures of Jesus in there. Oh, Carl, I know you have this picture of Jesus that we brought but can I hang this up in this room again? Where would you like to put it? .... So, Carl will go to church. Ahmm, the state does send down a bunch of different outings and things that they have going on. So, Bridges of Faith is having a pilgrim church annual Christmas event so, that comes down from my email. I print it out and I say, hey Carl, I know you like church. Would you be interested in going to this Thursday night?” (Caitlyn, Residential Program Director)

“He goes every Sunday.... I attend church because I am Catholic as well, and I go for the Portuguese part of it....so I attend church with him.” (Residential Home Staff)

“In church too.... Santo Christo Church on Columbia Street in FR.” (Dave, Individual with TBI)

“He invited me to see his room, and I couldn’t help but notice the different religious artifacts he had on his wall. He had the crucifix hanging next to this TV in his room, and he had a picture of Jesus also in his room.” (Field Notes)

### **Supported Environment**

Study findings indicated that transitioning individuals with TBI from a long-term care facility to a residential group home occurs in the context of having a supported environment. A supported environment is defined here as an environment where there is availability and easy access to community resources, as well as formal and informal supports (see Figure 24). The Medicaid waivers program creates such a supported environment with its’ in-built supports through the approved services in the community. Supports provided by peers, professional caregivers, families, and community service providers in a collaborative effort was also available during the process of transitioning to

the community. The availability of such a supported environment fosters a smooth transition, enhances the individual's satisfaction, and improves their well-being.

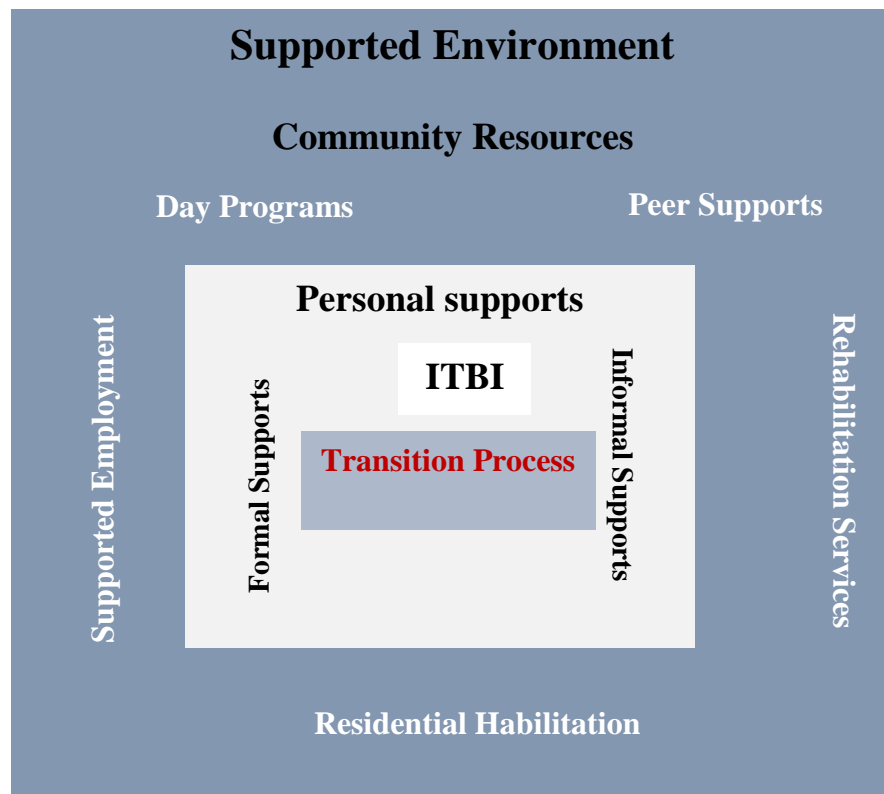


Figure 24: Showing a supportive environment within which the transition process occurs.

### **Community Resources**

Community resources is defined here as community-based waiver approved services and programs used to improve the quality of life of the individual with TBI transitioning from the long-term care facility. These services are provided mostly by state-contracted agencies. The services they provide include community-based rehabilitation, day program services, peer supports, personal care attendants, transportation supported employment, and home modification supports. It should be

noted that the residential group homes that the individual with TBI moves into are a waiver service and are referred to as residential habilitation. In this section, services emphasized by participants as most commonly utilized by professional caregivers and community service providers is presented. These include rehabilitation services, day programs, peer supports, and supported employment.

### **Rehabilitation Services**

Through collaboration with community-based agencies such as Massachusetts Association for the Blind and others, rehabilitation services are available and provided to the individual in the home and outpatient rehabilitation centers in communities across the Commonwealth. Rehabilitation services offered include physical therapy (PT), Occupational therapy (OT), and Speech Therapy (ST). During transitioning, an individual with TBI is encouraged by their professional caregivers, families, and community service providers to participate in rehabilitation to foster increased strength and independence.

“But once he got that new chair, I was like, okay, you got your new manual wheelchair so it’s time to start outpatient PT, OT so you can get stronger and that you can eventually do something during the day.” (Antonia, DDS Service Coordinator)

“She’ll do exercises with him. When A...e is there, he would, he’d send me videos of him having Chaos at the sink standing up. You know, doing stuff like that, these little exercises that PT gives him to do in the house....” (Glinda, Family Caregiver)

### **Day Program**

Day programs are one of the widely established programs that these individuals have access to while living in the community. Day programs are meant to be places

where the individual with TBI can go to socialize and engage with peers. At the day programs, they participate in varied social activities and small tasks to keep them busy and boost their self-esteem. Some of the day programs also offer simple exercises as rehabilitation. Participating in a day program is always encouraged, but predominantly remains a choice for the individual with TBI.

“Yeah, they do have.... the people within ABI or TBI go to a different day program, then those that are within DDS programs, that are intellectually disabled. So, they go to a different day program. And it’s their choice if they want to go to a day program.” (Joe Smith, Residential Program Director)

Though the provision of day program services through the waiver program is laudable, the individuals with TBI who participated in this study opted out of going to a day program due to various personal reasons. When asked, why they did not attend these programs, one individual indicated that it was not worth his time. He stays at the house instead, interact with staffs, watches television, and does other activities in the home.

“Dave does not go to a day program. When I asked why he replied, “I don’t think anything about that” and went on to say “I am happy here .... I like the place here.” Residential home staff spoke to him in Portuguese, and turned to me and said, “He likes the home setting. He doesn’t want to go to a program.” (Field Notes)

For another individual, it was because of a lack of interest in socializing outside of the home, even though he had tried other programs as well. Like his counterparts, he likes to spend time in the home.

“Yeah, my dad's not like a social person. He never was, so it's not like him to sign up for a day program. We tried a couple of things at the beginning. He tried physical therapy. He tried volunteering at an animal shelter. And he just didn't like it and at the end of the day. Well when they wouldn't let him have a cat, he didn't like it, so he gave that up.” (Chossey, Family Caregiver)

## **Peer Support**

Peer support was another community resource available to waiver participants. Peer support is a service that professional caregivers tend to use as an alternative to day programs in order to foster more social engagement in the community. With peer supports, a peer from the community comes in to spend time with the individual with TBI and take them out into the community to engage them in activities such as shopping, visiting recreational parks, etc.

“They tried the day program, and it’s something that’s just not for them. Okay, why don’t we try hands-on peer support. What is peer support? It means that you can have somebody 16 hours a week. They’ll come in 4 hours at a time and they can take you out to the community. They can take you shopping; they can take you, you know, you want to go to the lake for the day, that person is there for you. So, I try to use those three avenues.” (Redsox, DDS Service Coordinator)

## **Supported Employment**

Supported employment is a program that allows the individual with TBI, the opportunity to work in an integrated work environment and engage in modified-tasks with accommodations. Supported employment promotes vocational rehabilitation for the young and middle-aged individuals with TBI who yearn to go back to work. During the transition process, the professional caregivers and residential service providers, worked hard to encourage the individual with TBI engage in such programs, in order to foster their community re-integration.

“They get training. Some supported employment will provide a job coach. I have two individuals right now who are doing supported employment.... So, you know, the supported employment will work with the person and meet the person where they’re at. And understand their physical limitations and whatever modifications need to be made so that the person can do the job. You know what I mean? But they don’t throw too much on the person. You know what I mean? They’re not going to ask you know, someone in a wheelchair, can you please lift this 75 lbs.



bag, no they're not going to do anything like that." (Redsox, DDS Service Coordinator)

### **Personal Supports**

Besides having in place community resources that helped foster a supported environment, individuals with TBI also received personal support from family, professional caregivers and residential home staff, as well as other community service providers. Personal supports are defined here as the services given formally to the individual by professionals and/or informally through family caregivers, friends, and peers.

### **Formal Supports**

Formal supports were provided throughout the transition process as DDS service coordinators and other community-based service providers, including nurses, interacted professionally with the individual with TBI. They provided formal supports in the areas of case management and follow-up services, education, counseling, and direct hands-on care. Such supports were valued by the individual with TBI, as it helped foster stronger relationships and rapport.

"Sometimes they just need a little us support from us.... Jay, being with a brain injury, for whatever reason, thought it was back in the 70s where you can smoke in a theater ... I don't know if he did that on purpose or if he really thought it was ok to smoke a cigarette, but our staff was like.... you can't do that, you got to put it out, we're going to get kicked out. He was redirected, and it was fine. So, they just need that support from us. They need that help from us. And when we're transitioning people in, making sure that they know that those supports are going be here." (Caitlyn, Residential Program Director)

"And for him, it was really good for him to know that they were there, you know, because he was sick. I mean, it was like, like they were just as crushed as I was....

that you know what he was going through.... he was having a hard time breathing and stuff....” (Glinda, Family Caregiver)

### **Informal Supports**

Like formal supports, the individual with TBI also relied on informal supports from family and friends. Unfortunately, not all individuals have supportive families or friends, and rely mostly on their formal supports from the residential staff and their other professionals. Sometimes, other families of their housemates stepped in to provide them with some informal supports and brought food or goodies for them. For those who do have family and friends, they receive support from them as well. The informal supports received include financial support, advocacy, and emotional support. All three individuals with TBI who participated in this study received informal supports from their families.

“So, the family is there for support mostly, if they have any family. Ahmm, most of our folks don’t have anybody. So, it’s just the person and DDS looking out for their best interest.” (Cassandra, DDS Service Coordinator)

“When her sister-in-law would come up from Virginia, they would go every day to visit with him. Or he had some family friends that had dogs and pets, and he was a pet lover. They come on the weekends or take him outside in the courtyard and let him play with the dogs. Or they would race.... he liked to race remote control cars. They would do that. But she was a very involved family member.” (Antonia, DDS Service Coordinator).

### **Process Timeline**

The process of transitioning an individual with TBI from a long-term care facility to a residential group home in the community is an ongoing process, as this becomes the permanent homes for many of these individuals. For others, this process is a stepping stone upon which they trod to other opportunities, for a more independent living situation. This process of transition starts from the pre-transition phase and moves through the continuum as shown in Figure 25.

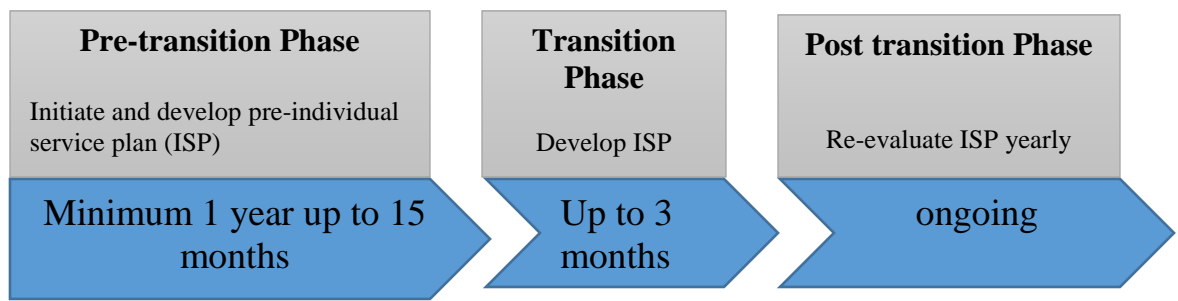


Figure 25: The process timeline.

### **Pre-Transition Timeline**

The pre-transition phase is expected to last for about a year. However, due to many unforeseen delays with the construction of the houses for the residential homes, this phase can take up to fifteen months until move in (transition phase). Within this time, there were also specific set timelines. For example, the DDS service coordinators initiate the first transition meeting once they obtain a move-in date from the residential home provider. This occurs about two months before the move. A second transition meeting is held as the move gets even closer (about two weeks away). These set timelines are flexible and sometimes get moved, depending on the individual situation. If more

meetings are needed, this timeline will be adjusted to accommodate such changes as appropriate. (see Figure 26)

“So, the rule of thumb is that people are supposed to be placed within a year. That typically doesn't happen because agencies struggle with finding land, finding contractors.... you know, weather becomes an issue if they're building a new house. If it's a house that they're refurbishing, you know, you knock down one wall, and you're going to find a boatload of issues. So, it tends to last much longer than the traditional year that it should, and then about a month later we have a second transition meeting.” (Sue White, DDS Service Coordinator)

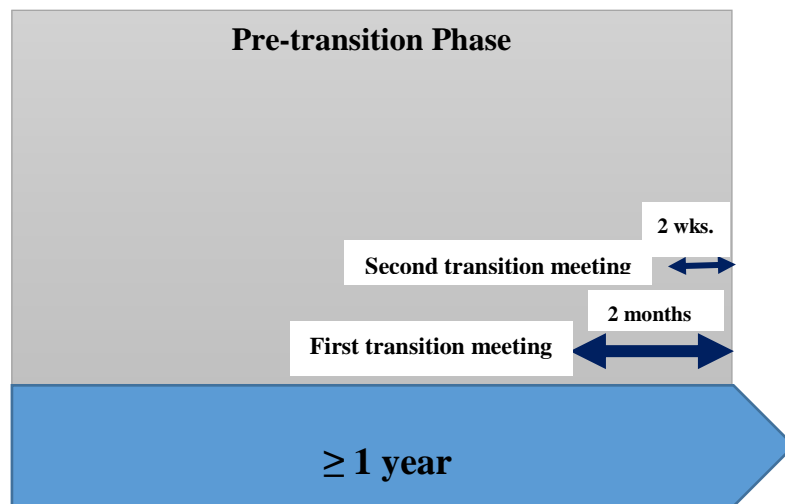


Figure 26: Set timelines within the pre-transition phase.

“You know, they can meet a provider and a home won't be ready for a year, year and a half, so the waiting time could be that long, or it could be six months. But you know, it's a huge window.... I would say at the two-month mark point before the house opening, but this could change too because they could have setbacks with buildings.... with the building, with codes, with the city, all the zoning laws and things like that. So, let say for all intents purposes, its two months out. What we do is, we schedule a two month out.... probably a first transition meeting. Well, after that first transition meeting, two weeks prior to them moving, we have a second transition meeting.” (Antonia, DDS Service Coordinator)

“We have anywhere between two to three transition meetings that take place over the course of two months maybe.... the second meeting, you know, happens maybe two to three weeks later....” (Jessica, DDS Service Coordinator)

Even though it takes a long time on average to go through the pre-transition phase, there are instances when this timeline occurs faster. For example, if a room becomes available in an already existing house, another person may be transitioned in, and in that instance the wait is short. The preparatory phase could take only about a month.

“... But if maybe you are placing one individual at a home which is already set for four people, it is easy because the house is there, the staffing, everything is in existence. Yeah, so once he’s eligible, and we find the provider to serve that individual, most of the time we have one or two meetings at the max. And they can take less than a month to have the person from the first transition meeting to be living in the house. So, it depends.” (Ubda, DDS Service Coordinator)

### **Transition Timeline**

This phase ends the pre-transition phase and starts at the day of move into the residential home. Unlike the pre-transition phase, this phase is not pre-determined but assumed, based on when the first actual ISP meeting is held (about three months’ post discharge). At this meeting, new and realistic goals are set to mark the start of their living in the community. Therefore, once the ISP plan goes into place, a new phase begins which is determined here as the post-transition phase.

“Ahmm, but just....and then, after that first three months, the agencies will do their assessments, and we’ll get an idea of what they wanna work on long-term.” (Sue white, DDS Service Coordinator)

“...and then three months in, after they move in, we have the first individual support plan meeting and that, in that meeting we kind of sit down.... I sit down before with the person and kind of ask them what, what do they see for themselves while they’re here? What, what are your goals in the next year, in the next five years, in the next ten years? What do you want to do with your life now that you’re not in the nursing facility, now that you have some freedom... what we call a vision statement....and building in supports that they’ll need to

eventually become more independent if they can be within their own home and the community.” (Jessica, DDS Service Coordinator)

### **Post Transition Timeline**

Post-transition starts once the individual service plan is drawn and put in place. This phase is ongoing until there is some significant change for the better, or for the worse. In some instances, individuals acquire more independent living skills and may move on to an appropriate setting. Others may become too compromised due to failing health and may have to transition back to the long-term care settings, or they simply may die. In a few instances, an individual cannot be safely served due to significant behavioral issues and may have to leave the house for fear of harm to others in the home. But for the majority, living in the community is ongoing.

### **Summary**

From the description given by study participants of the transition process, it was evident that this process is not only complicated, but it is meticulous, and a well thought out process with a fluid timeline. The checking-in stage of pre-transitioning sets the pace for this entire process, and it is characterized as a phase of getting to know the person through information seeking, gathering and sharing, as well as relationship building. This process, together with collaborative planning, enhances preparation for a good transition. Orientation through meet and greet and the provision of a safe and welcoming environment enhances a smooth adjustment for the individual with TBI during the move-in phase of the process, as relationship building is further improved. At the final phase of the process, the routine aspects of the individual’s life such as maintaining health,

socialization, work, and spirituality are fostered. Also, at this final phase, stronger relationships are built and the individual with TBI is happy and living comfortably in a supported environment where there are available community resources and personal support from professionals, families, and friends.

Given that this is an optimal goal and a dream for many involved in the transition process, such a smooth and seamless process was found in this study as not always plausible. This is because the process is influenced by many factors. In the following chapter, a detailed description of both the facilitators and barriers to this process will be reported.

## CHAPTER 8

### FACTORS INFLUENCING TRANSITION PROCESS

#### Introduction

The process of transitioning is a complicated process that is influenced by myriad factors including supports, health and functional abilities, environmental factors, and facility and market factors, as suggested with the review of the literature (see Chapter 2). These factors, though based on long-term care transitions, was limited to older adults with other chronic illnesses and not TBI. Determining the factors which influence such transitioning helps to ensure a successful transitioning to the community for individuals with TBI from long-term care facilities.

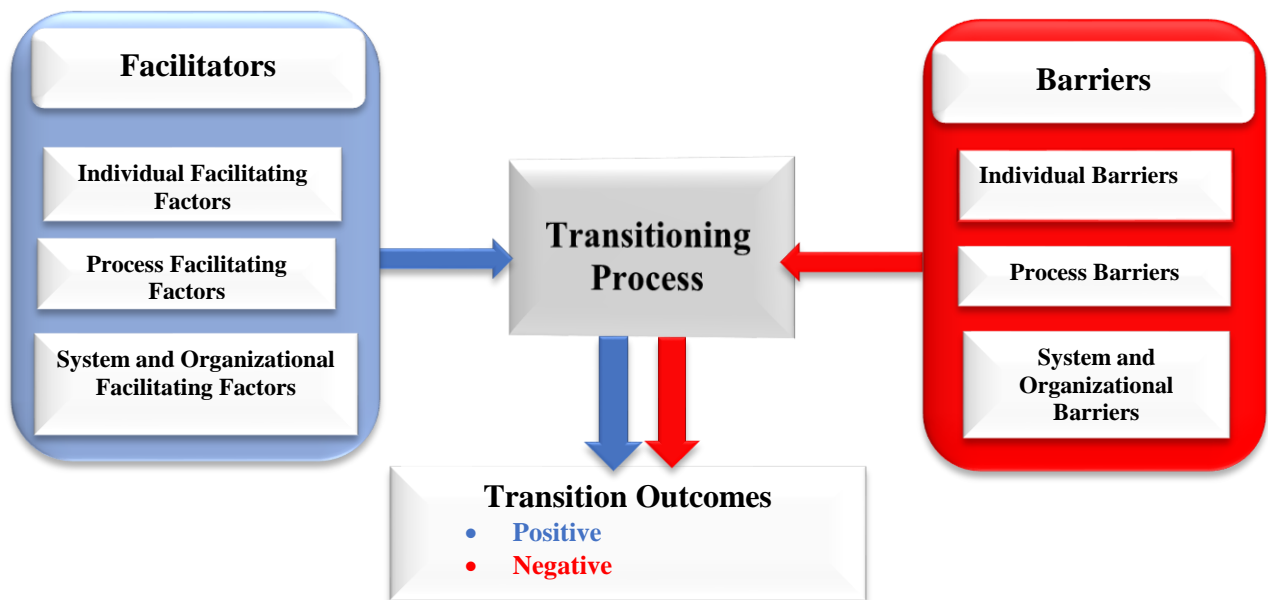


Figure 27: Factors influencing the transitioning of individuals with TBI from long-term care facilities to residential group homes in the community.



In this chapter, findings on the factors that influence transition obtained from the perspectives of the individuals with TBI, their family caregivers, professional caregivers and community service providers who are directly involved with the transition process, is presented. (see Figure 27)

### **The Facilitators**

These are the facilitating factors that directly influence the transition process. These factors positively affect the transition process, as described by the individual with TBI, the family caregivers, the professional caregivers, and the community-based service providers. In this study, the facilitating factors were categorized as individual facilitating factors, the process facilitating factors, and systems and organizational facilitating factors. Each identified category is made up of many themes and subthemes, as is depicted in Figure 28. A detailed discussion of each of these categories with the identified themes is discussed below.

#### **Individual Facilitating Factors**

The individual facilitating factors found in this study are the factors that directly involved the individual being transitioned, and in turn, had a direct or indirect positive effect on the transition process. Such factors included positive individual attitude to therapy and family involvement.

### **Positive Individual Attitude to Therapy**

Having a positive attitude to therapy was one of the facilitating factors that impacted overall transitioning outcomes. According to community-based occupational therapists that work closely with individuals in residential group homes, individual outcomes were successful when their attitude to engage in therapy was positive. Positive attitude was showing the motivation to engage in therapy, to walk again, to use the toilet, or to be able to self-transfer.

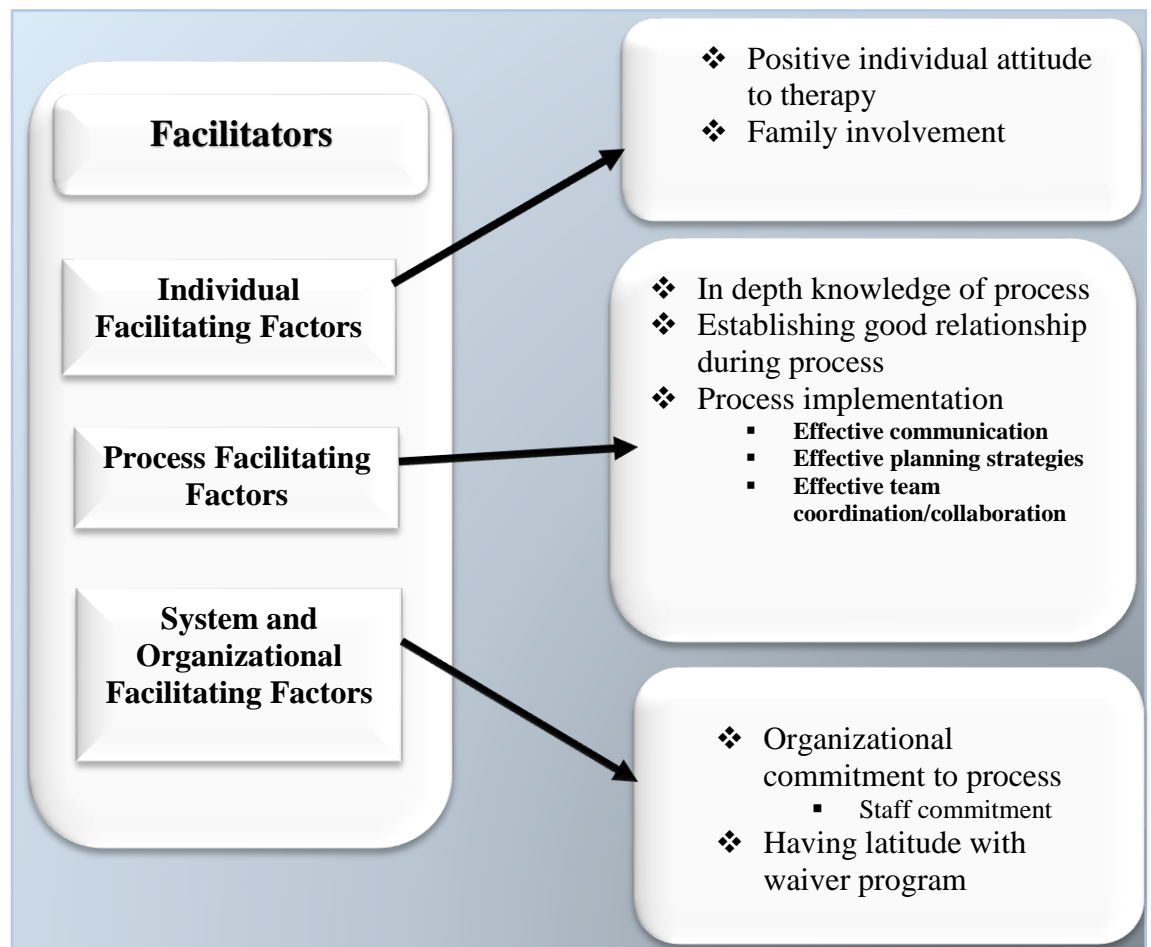


Figure 28: The facilitating factors influencing successful transitioning.

“A lot of individuals want to stand.... a lot of individuals, ahmm, want to be able to use the toilet instead of a bedpan, or to transfer.... like, that's really motivating. Ahmm, and a lot of them want to walk and, you know, but we start with something that's very meaningful for them in that way. Success, ahmm, I kind of.... it's been really tricky cause you don't always see a huge change or a huge like, ahmm, we're going to work on this and that it keeps happening. But what I find is staff and or the clients enjoy having me come. They like having me there they look forward to doing something with me. I find that to be a huge success because a lot of times I feel like we're one of the biggest joys that they have....” (Alyssa, Occupational Therapist)

One occupational therapist went further, to indicate that individuals' eagerness to participate in therapy and their plan of care, very much influenced success.

“I think success is, is pretty much dictated by a client being happy to see you and wanting to participate in what they know is their plan of care, to help them meet their goals.” (Dee, Occupational Therapist)

### **Having Family Involvement**

Study participants expressed the importance of involving the family in the process. Some professional caregivers felt that having family involvement or some social network positively influences the transitioning in the long term and makes the individual successful.

“So, we, as an agency, we like to make sure that families are very involved in that. The individual is able to move to a location that's closer to their family, you know, that's our priority. You know, we feel like, you know, looking at a long-term basis, people are more successful if they have some sort of a social circle, and we attribute that to a family structure.” (Rudy, DDS Service Coordinator)

One community-based service provider expressed how a committed family made it possible to successfully transition a very complicated individual with TBI out from the long-term care facility to the community.

“And if.... the family that.... that with the young child, they were the best family ever, like really! They were so committed, and they were so wonderful like that. It

was like, if we can get this kid out, we can get anybody out.” (Kennedy, Transition Coordinator)

Some participants felt that the more family was involved in the individual’s life, the more they were willing to get involved and perhaps participate in other activities.

“Well, the more involvement from the family and friends, the more involved the participant is going to be. You know what I mean? If the family is not that involved, the person is not going to be that involved themselves. You know what I mean? You know, the more support that they have from family, the better. It is how I feel, you know what I mean? And they’re kind of like in that depressive, you know, in a depression type of mode because they’ve been ignored by their own family for so long. Why do I want to go out, my family doesn’t even come to see me. You know what I mean?” (Redsox, DDS Service Coordinator)

One participant noted that family involvement was dependent on the extent of the prior family relationship with the individual. A good relationship before injury often stood the test of time and remained good well after the injury.

“It depends on the history. It’s a per case basis. I would say more often than not, if they were involved in their lives pre-accident, they are still involved in their life post-accident. If it was a rocky marriage before the accident, it’s most likely over post-accident. With that, you know, it’s usually what happens. So... But if it’s good pre, it’s good post, that’s what I see.” (Chip, DDS Service Coordinator)

Having family was often beneficial to the individual because family provided extra supports.

“So, the family is there for support mostly, if they have any family. Ahmm, most of our folks don’t have anybody. Family sometimes will be their rep payees. Ahmm, if they have like a sister, who doesn’t have any legal obligation to anything, will offer to manage the finances and ensure that his rent gets paid, his pharmacy bill gets paid, ahmm, he gets his \$200 a month for personal needs spending. Families usually go well beyond \$200, and they will go and purchase their clothes and anything that they want. Ahmm, some families are capable of doing that. Ahmm, a lot of them are ....” (Cassandra, DDS Service Coordinator)

Families also acted as strong advocates and helped ensure successful transition outcomes for their family members. Families advocate to get their loved ones out of the nursing

facility to the group homes, which are much smaller settings so that individuals can get one to one attention.

“His sister was a strong advocate for him to come out of the facility. He was young. He was in his 50s. Ahmm, she felt that he would be better in a smaller environment and wouldn't feel so lost or, you know, just that more one on one attention would be better for him. Ahmm, she definitely felt that going to the home that he went to was closer to her and she would be able to visit more. She did visit and meet with him and then talk to the people that were managing the group home, and you know, get a sense of what they do for folks there. So, it gave her more information so that she could reassure her brother.” (Rose Quartz, Facility Social Worker)

They also advocate to ensure that their family member's safety is supported, and their needs are met while they live their lives in the residential group home.

“Twice, which is why I made a big deal about the violence here. I mean when that was happening, and I said he's already been a victim of violent crime twice. He does not need to be victimized in this house. Like.... I'm not going to stand for this. I will take, you to court and we'll fix it in court. So, it's fine...” (Chossey, Family Caregiver)

“Ahmm, I don't, because I'm like Mama Bear. You know what I mean? And he'll tell you too. Like, if something's going on that he's not happy about and then I get involved. And then once again taking care of things for him, like when he was younger. You know, him being my son.... I've just, I've always thought.... been his biggest advocate, regardless of what was going on. I can't imagine not being involved or knowing what's going on.” (Glinda, Family Caregiver)

### **Process Facilitating Factors**

The process facilitating factors are the factors that influence how the transition process is managed, and consequently, impacts the outcomes of transitions positively.

The process facilitating factors identified in this study include: 1) having in-depth knowledge (knowledge about process and knowledge about individual's needs); 2) establishing a good relationship during the process; and 3) having good process

implementation strategies such as effective communication, effective planning strategies, effective team coordination, and collaboration.

### **Having an In-depth Knowledge**

Having an in-depth knowledge of the process was one of the leading factors that influenced the process of transitioning individuals with TBI from long-term care facilities to the community. Professional caregivers (especially the service coordinators) demonstrated an in-depth knowledge of the process as well as knowledge about the individual and their needs. Study participants described different instances where such knowledge and expertise were displayed.

### **Knowledge About the Process**

Knowledge about the process was evident by the expertise professional caregivers showed in coordinating all aspects of the transition process. Professional caregivers interviewed, were concrete in their decision making, indicating a deep understanding of all elements of the program. For example, they were informed regarding Mass Health requirements and knew which forms to complete, so that the transition process was seamless.

“To make the process seamless, one has to have good knowledge about the process regarding the underlying insurance provisions, the forms to send to who, etc. Ubda indicates the SC-1 form which has to be faxed by the nursing home to Mass Health, so they can start covering the individual in the community. Failure to do so will be detrimental to the process, as things like incontinent supplies and diabetic supplies will not carry over. Ubda indicates waiver provides intermediate coverage for 3 to 4 weeks, which ensures some time to see a PCP in the community and get new scripts to be covered by Mass Health. These actions described gives an example of how just knowing and understanding the process can foster a seamless and smooth transition.” (Field Notes)

Professionals also demonstrated good knowledge about managing medications during transitions. For example, the format required for the prescriptions to be written per the Massachusetts Medication Administration Program (MAP) guidelines.

“Yeah. Most of the group homes they have a MAP, Massachusetts Medication Administration Program, but it does not apply that way in the nursing home.... most of the time we actually tell the provider to prepare the way they want the script to be done, and they give to the nursing home. So that the nursing home will write it exactly and then the doctor there can sign. The order has to reflect exactly how the MAP program requires it when they go to the group home setting.” (Ubda, DDS Service Coordinator)

Furthermore, their knowledge about the services and resources available under the waivers and in the community came through during the interviews. They showed an understanding of how to effectively coordinate services and resources and put them in place to ensure continuity of care and a smooth transition process.

“They'll have to have a physical exam within the first two weeks of them moving. So, the provider nursing team will usually set that up before they even transition out of the nursing home. Then sometimes, depending on what their other needs are, if they need a specialist, if they don't already have specialist in the community.... we will have their new PCP refer them. If they need a cardiologist or a neurologist, some of them already have the providers and the....and if we can use the old providers like the neurologist, the cardiologist or whatever specialty, the endocrinologist, we will use those but if not, we'll look for another new specialist in the community in their.... closest to their home if that's what they want, or a hospital of preference.” (Antonia, DDS Service Coordinator).

They also demonstrated in-depth knowledge of how to coordinate and work with a team to ensure successful transitioning.

“Everybody knew how to coordinate their piece of things, because you knew how the supply company needed the [order to be written] and how to receive it, and they [the DME supplier] could tell people—the nurse need to order this, so just ...have the doctor write that, and this is how therapist has to write it. We had their books [company supply catalogue] there and the patient themselves was there...

Do you think something like this would work for your shower type? the therapist would say, if they felt that, that, was the one that fit the shower type, and was going to be the safest one for the individual.” (Ava, Facility Social Worker)

Such in-depth knowledge helped them in being creative with scheduling the date of transition. Such creativity helped to ensure that there were no hiccups in the process and that the transition was smooth. For example, one service coordinator laid out his thought process in coordinating a smooth transition to the community. His thought process and strategy showed a deep understanding and affirmed his knowledge of the process.

“I try to have people discharged at the beginning of the month because I’ll know that they have the rest of the month of meds to go home with. So that’s why I like to discharge at the beginning of the month.... because just in case they couldn’t get that appointment within the two weeks, at least we have the rest of the meds for the rest of the month left over that they went home with. If I did that at the end of the month, let’s say it’s at the end of the month.... let’s say I did it on 20th.... they have ten days of meds left. And let’s say the person can’t get into the PCP until two weeks later. What are we going to do for those four days that they don’t have meds? So that’s why I like to discharge at the beginning of the month. Because I have the rest of the month of those meds left over for that person on the day of discharge.” (Redsox, DDS Service Coordinator)

Having in-depth knowledge of the process helps foster a smooth transition, so professional caregivers made an effort to learn about the process. Learning was on the job and through formal training and mentorship.

“I do feel that your knowledge base does help the process and I, like coming in being new.... I knew nothing about the waiver. So, coming in and getting acclimated to it like you said, you’re going into these meetings and you’re hearing what these teams are asking for and, as you keep working with agency after agency, you learned the little things that make a meeting go even smoother. So, as we are growing in our roles, I feel that we’re becoming even better because we’re learning.... because each individual, like I said, is different so it’s going to pull different things from each team that we’re meeting with to make this transition successful.... which can go into other future meetings because you just learned something. Like learning that you need two weeks of meds. I might use that



moving forward, which would help that transition go even smoother you know or learning all the different....” (Tina Marie, DDS Service Coordinator)

“Like each case taught us everything we know right now.” (Luz Marie, Transitional Coordinator)

“It was a learn as you go for everybody. It wasn’t just us.... Everybody.” (Summer, Transition Coordinator)

“This was impressive because they are not nurses. This shows the level of training these service coordinators have received. She indicated that they use a tool [a transitional packet that guides them].” (Field Notes)

“But we had training once at the beginning, way when I first started, that is described step by step. And I think I have my notes. Ahmm, how.... what.... how a consumer falls into ABI.” (Luz Marie, Transitional Coordinator)

“I let newer service coordinators run them, but anything that comes up that they can’t answer.... I will, you know, answer. I’ll suggest ideas. I’ll make sure that, you know, things that need to be in.... put in place are put in place and addressed. And I take notes at the same time. So, if they.... the person who’s running the meeting needs to refer back to my notes and their notes they can.” (Antonia, DDS Service Coordinator)

### **Knowledge about Individual’s Needs**

Aside from their in-depth knowledge in managing the process, most professionals also demonstrated vast knowledge about the individual needs. During this study, participants stressed the importance of having knowledge about the individual’s needs, which helped them to efficiently plan for transition.

“What their needs are. We have to really know and understand what all the medical needs are. If we have individuals that might have a Trach, or they might have G-tubes, what are the specific training that is going to be required from the agency to the staff to support this individual.” (Joe Smith, Residential Program Director)

“So yeah, so we try to do it that way to make sure the transition is clear.... I read about his background before I go for transition meeting. I just want to ...make sure we don’t miss anything in terms of those areas of their needs, and all other medical needs. Somebody can have TBI and also got blood pressure, diabetes and

everything.... Therefore, we make sure that all those services are in place before we move that person from the facility.” (Ubda, DDS Service Coordinator)

### **Establishing Good Relationship**

Having good relationships and rapport among team members, including the individual with TBI and their families, community-service agencies and staff from long-term care facilities, helped foster a smooth transition process.

“Sue stressed the importance of maintaining rapport and relationship with the person with TBI. She implies that it is important to build that relationship because come the actual move to the community, they will need a point person who will be assisting them and acting as a liaison between them and the group home. Why is this important? I guess once trust is established, the process will be emotionally seamless for them.” (Field Notes)

“So, ahmm, our relationships with those vendors are very important (laughter 44:02). So, I have one vendor that I always go to right now and she is.... they’re phenomenal. I think it depends on the area. I use Easter Seals only because I have a good relationship with, ahmm, the main guy. I use him a lot, so he's very responsive to me, and he gets them out there really quickly.” (Cassandra, DDS Service Coordinator)

“So, it's just trying to mediate between the guardian and the provider agency that's going to be providing services because you don't want to, you know, ruin that relationship. You know the guardian needs to have a good relationship with the provider agency.” (Sue Smith, DDS Service Coordinator)

“I mean, I’m like literally.... first-person transitioned home with the G-tube and no food. Like, I didn’t.... we didn’t really know what we were doing. But, and then saying that none of us are clinicians, we were so successful. And I’m....and I think it was because of our relationship with social workers and Charm.” (Kennedy, Transition Coordinator)

Building a strong relationship and rapport with vendors helps to ensure that all supplies get delivered on time for a smooth transition, even under very dire circumstances. A conversation with one of the service providers indicated the importance of such relationships in fostering a smooth transition process.

**Sylvia:** “It looks like each of you have kind of built your own rapports among the providers.”

**Cassandra:** “Yeah”

**Sylvia:** “And you know who to call at what time, and you know who.... who will deliver, and all that stuff.”

**Cassandra:** “Yeah, yep. ahmm, there's been times that one transition that I put off.... I had five transition meetings. The bed was never picked up and it was never ordered....and it was according to the nursing home, which I can't verify, if they did it or they didn't. They just said that they had ordered it and it was to be delivered and it didn't show up. They moved him, picked him up, and they said it was supposed to be there that day. It never showed up

**Sylvia:** “What did you do?”

**Cassandra:** “So, I had.... I have a good relationship with another provider.... another vendor, and I called her. And she was able to get me a bed immediately.”

### **Having Good Process Implementation Strategies**

Having good implementation strategies helped to foster a smooth transition from the long-term care facilities to the residential group homes in the community. Some of the implementation strategies used by the professional caregivers and other members of the team during transitioning included effective communication, planning, having effective team coordination, and collaboration.

### **Effective Communication**

Effective communication strategies were described by most study participants during this study and were shown as an important facilitating factor for a smooth process. Communication, according to study participants, was the most important marker to successful transitioning.

“If the communication is effective. That's one thing I've come to learn is that when we've had difficult cases and you go back, and you go through and you comb through, you will find that the communication broke down somewhere and that's where the problems have been coming in. So that's why I told you

communication is the biggest.... biggest thing throughout this whole entire process.” (Tina Marie, DDS Service Coordinator)

“There is no straight-up way of doing the transition, but communication is the major thing to try to bring the team together.” (Ubda, DDS Service Coordinator)

“I think that kind of communication and, ahmm, continuity of the.... the true continuity of care would make a difference.” (Rickie, DDS Service Coordinator)

### **Effective Planning**

Planning was another strategy used by professionals to manage the transition process. There was a lot of planning involved in successfully transitioning an individual with TBI from the long-term-care facility to the community. Planning was centered around developing a plan of care, finding individuals’ needs, and figuring out how to get them the right equipment, services, etc. needed in the community. Effective planning helped in ensuring a smooth and seamless process because, during the planning process, problems were found, and strategies were put in place to help mitigate those risks, thus leading to more successful outcomes.

“And what you’re going to do for some sort of plan for that. So, you’re looking at the whole big picture and then mapping out how you’re going to meet each of those needs. And what services are you going to put in place, and what people are you going to put in place to help with all those needs, and how much does that individual want from you. What are they going to accept?” (Ava, Facility Social Worker)

“The provider has to provide transportation for the person to get home with all their belongings from the nursing home. So, they have to make those plans and those arrangements.... Ahmm, I have stopped transitions because it was an unsafe discharge with nursing homes because they fail to get the equipment or get a wheelchair to send them home in. There’s a lot of details that go into it.... a lot of planning.” (Cassandra, DDS Service Coordinator)

### **Having an Effective Team Collaboration**

Having an effective team also enabled a smooth transition process. It was obvious in this study that if team members were all on the same page, they were able to collaborate and coordinate services more effectively and transitions were easier and smooth.

“MFPs has been so successful as opposed to like you know the one care model is because of like the-the intermediary or interdisciplinary care team you know that like everyone is on... the same page, we're all in it together as opposed to...” (Kennedy, Transition Coordinator).

“Once we call our self, team joe that usually works perfectly. But to get there, it can be a little tricky sometimes.” (Ubda, DDS Service Coordinator).

“Yeah, I think because.... I think with the waiver program, when you have all the different, ahmm, disciplines that are going to continue either to follow or pass on information they get from the team, at the facility it transitions.... it's just an easier, a smoother transition. It's a better continuity.” (Rose Quartz, Facility Social Worker).

### **System and Organizational Facilitating Factors**

System and organizational facilitating factors are factors that involve the organizational structures of government and private organizations and positively impact the transitioning process. Such factors include organizational commitment to process, having latitude with waiver program, and it depends on the house. These factors will be described as follows.

#### **Organizational Commitment to the Process**

Organizational commitment often came with having collective buy-in from the management and staff of the organizations with whom the professional caregivers and

community-based providers had to interact. When such buy-in existed, staff showed commitment to ensuring success, and there was often follow through with recommended treatment plans and protocols, which in turn fostered desirable outcomes. For example, the therapists were willing to work more effectively with the individual with TBI when they had such collective buy-in and felt they had a connection with the staff in the home.

“And there's a very big difference. I have a very different rule with some of the houses than I do with others and-and it all comes back to that. Yeah, right.... it's the house. So, I can work on standing with one particular person, because everybody has bought into it. I am not doing that with another person. I'm not doing extra referrals, getting extra equipment.... ahmm, orthotics, wheelchair assessments, going to see a psychiatrist, addressing the tone. I'm not doing that in another house at all because I don't have that connectedness. I don't have that buy-in. I don't have that.... I don't have any of that.... none of the relationship with any of the people there. But I do in another house, and so those particular individuals or that particular individual seems to be getting a lot more of my energy because of that.... because there is a collective buy-in.” (Isadora, Occupational Therapist)

### **Staff Commitment to Process**

Having staff within an organization that was engaged and committed to the transition process also helped with the transitioning. One service coordinator described commitment and dedication shown by one of the nurses to ensure that an individual was ready for transition.

“This person was there for them, and they wanted to see him succeed.... and they were going to do anything and everything, and they followed up with the CNAs, and they would sit there with those people and work with them hands-on, regardless if they had a 100 meds to pass or a 1000 notes to write, they...she took the time out of her busy schedule in a nursing home with..., I think her floor.... she had 50, 60 people.... a lot of call-outs, a lot of staff turnover over there. So, she was working very, very hard.” (Cassandra, DDS Service Coordinator)

Family caregivers expressed some frustration that when individual plans were developed, the implementation was often difficult, as it depended on which staff in the house was

committed enough to follow through with the plan of care. This reiterates the fact that success very much relies on the commitment of staff as well as the larger organization.

“Every time we have ... his individual plan meeting and you know, this [the plan] is, we're going to do this, this-this-this and this and it's all set up to go, and then, it depends on who's working there and who will do it with him.” (Glinda, Family Caregiver)

### **Having Latitude with the Waiver Program**

Participants expressed having great latitude in providing the best treatment options, as they felt the waiver was flexible and allowed the program participants (individuals with TBI) the ability to have access to, for example, best medical equipment and services to improve their functional ability and make them successful in the community.

“So, having this ABI program allows the latitude to....to say, let's raise the bar up. You want this. We can do that and then they, you know, are able to practice an activity that they haven't been able to do before. There is a lot of latitude to say this person needs a walker. I'm going to get them a walker, and we're going to start standing. Whereas if we were in a medical based facility, that couldn't happen .... as said.... it's the lowest cost item, and it's not effective for them. And so, a part of this process has this latitude to look at the whole function of the individual so that we can go do additional referrals and get them better-supported devices they need ....” (Isadora, Occupational Therapist).

“And as I said, waiver.... the good thing about waiver is, like, anything which is regarding the respiratory because they use in trach and everything. So, we try to use every new machine we can get, and the waiver usually is willing.... any invention comes, we try to make sure we see them. We go and see them, and the waiver usually will pick it up. So, they're getting better a lot.” (Ubda, DDS Service Coordinator)

Having such latitude with the waivers often afforded the individual and family opportunities that they otherwise would not have because of the financial cost associated with such services.

“Oh, definitely, yeah oh yeah, because my dad was no longer eligible for physical therapy, but the waiver allowed him to be signed up for physical therapy again even though he had expired all those avenues. And, ahmm, although he didn’t... wasn’t interested in it when we tried it, for whatever reason, at least he was offered the opportunity. In this, there were plenty of other opportunities that he was offered, and just he’s not interested in that. So that is pretty amazing, that they can do that and now they can buy.... Before, I bought his wheel chair for ten thousand dollars, but now they could get him one through the program. Ah well, I think that this was.... this is much better coordinated and there's a lot more money involved in this than what most people get, honestly.” (Chossey, Family Caregiver)

### **The Barriers**

These are the factors that presented as obstacles during the process of transitioning from a long-term care facility to the community. Such obstructing factors often had a negative or suboptimal impact on process outcomes. The barriers presented here represents the perception of the individual with TBI, family caregivers, professional caregivers, and community service provides. Field notes generated during this study will also be used as evidence to describe some of the obstructing factors. The barriers identified in this study are categorized as: 1) individual barriers; 2) process barriers and; 3) systems and organizational barriers. Themes and sub-themes under each category are depicted in Figure 29.

### **Individual Barriers**

Individual barriers are the factors which directly involves the individual transitioning and hinders the transition process. Such barriers found in this study include individual’s health and functional ability, institutionalization effects, inappropriate behaviors, inadequate family/guardian involvement, and having negative perceptions of the individual. Each of these factors will be further described as follows.



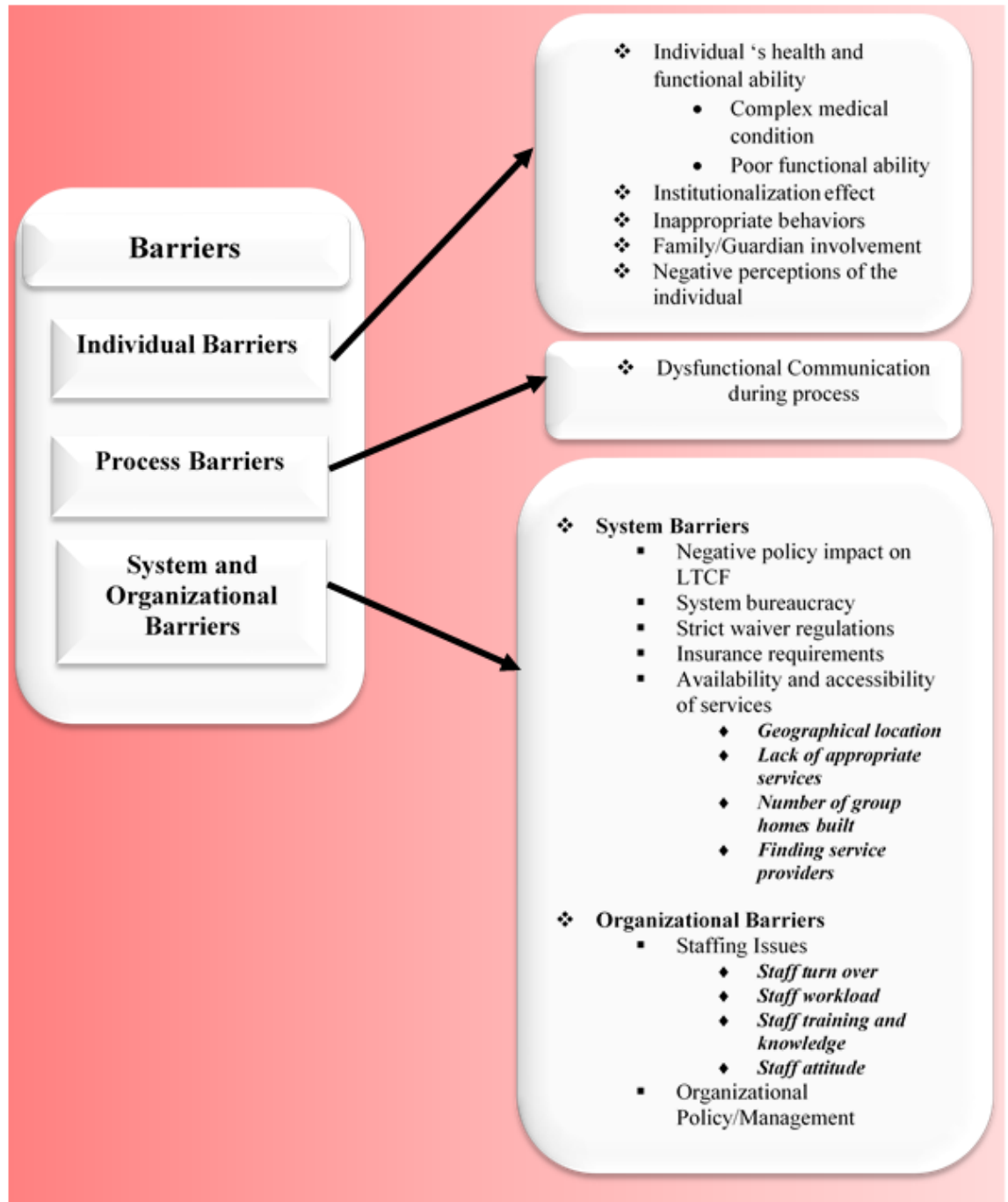


Figure 29: Barriers influencing the transition process.

## **Individual's Health and Functional Ability**

### **Complex Medical Condition**

Individuals who had complex medical needs and poor functional ability were often denied placement by residential home providers, as they could not meet their care needs in such settings.

“.... the other one was denied because he declined. So, they retracted their acceptance of him.... they couldn't meet his needs. He is a brittle diabetic. He needed glucagon shots and to get him to come back to consciousness, ahmm, he needed 2 of them every single night to get him back. Ahmm, he has cancer.... on his face, skin cancer, but they've been removing it. He's got kidney failure. Ahmm, he's just a hot mess.” (Cassandra, DDS Service Coordinator).

“He did get pneumonia a few times while he was there. He's was actually on hospice at one point, and they didn't know he was going to make it. And so, some of the provider agencies that we refer him to you said “how can we provide Heimlich maneuver to somebody that he's not sitting up to eat?” So, they don't want to take on that liability. So sometimes they will decline to take some of the folks that we're referring if they have had a status change.” (Sue Smith, DDS Service Coordinator)

“.... not always perfect. Some people are denied by one agency or another due to different, you know, medical difficulties, or you know, their status of their health at the time being. Or they get pull back a little bit” ... (Jessica, DDS Service Coordinator)

Many of the residential group homes are unable to provide 24 hours and 7 days a week care in their settings as they do not have nursing staff around the clock. Yet many of the individuals with TBI require such a level of care.

“Ahmm, but he.... the nursing requirement that came out of here is 24-hour nursing and right now no provider can provide 24-hour nursing.” (Cassandra, DDS service Coordinator)

Many of the residential group homes provide up to twelve hours of nursing oversight. For example, a nurse visits the home and ensures that medications are being administered by the MAP certified staff in the home. They do not perform direct care,

therefore all complex skilled nursing needs are provided through the local visiting nurse agencies when needed. Thus, many of these homes that do not provide 24/7 care, refuse to take on the medically complex patient, which often presents a significant barrier to transitioning individuals with TBI.

“If an individual requires some interventions, the local visiting nurse agencies may be used. First aid, all that stuff. But any complex medical things like giving an injection.... a lot of providers won’t take those people on unless they have VNA services that will be approved because the nurses will not be doing injections at those provider sites.... because they don’t have the nursing. They have oversight hours, which is basically to go in and make sure that the meds are being been passed, and people are following the medical protocols in place. But they are not doing hands-on.... on the individuals. But if.... if it’s not a 24-hours nursing provider home, they are going to shy away from those complex medical cases because it’s again the direct staff that are performing those procedures and they’re not going to want to put anybody at risk, whether it’s their staff or the individual they’re serving.” (Chip, DDS Service Coordinator)

Despite these barriers, a few residential group homes try to take on individuals with complex medical issues and try to manage them in the settings. Some have been successful, but others have also failed because individuals continue to deteriorate due to their non-compliance and end up back in the nursing facility.

“I have another individual who has stage 4 wounds. And he has a wound that he’s had for years. And he’s not compliant with his colostomy, and so it continues to get re-infected. In fact, there was an issue of sepsis at one point in time. So, he was placed very briefly in the community, and then when the wound care specialist will come out to do the dressings, he would refuse. He ended up back in the nursing facility.” (Sue Smith, DDS Service Coordinator)

### **Poor Functional Ability**

Some of the individuals with TBI who transition out of the long-term care settings to the residential homes have significant functional impairments or disabilities. They

often require assistance with most of their Activities of Daily Living (ADL's) and Instrumental Activities of Daily Living (IADL's). This sometimes can be a barrier to their active participation in the community after they move into the community. One individual with TBI refuses to go out and participate in any activity because he is unable to self-transfer to a toilet and is afraid of not being able to use one if he needed to.

According to his mother, this has been one of his biggest barriers to enjoying a full life in the community.

“You know, I mean, it's a.... that's his self-image and it gets in his way. It definitely gets in his way. But another thing that prevents him from going out and going anywhere and doing things is he has a problem with when he has to go to the bathroom. He's afraid he's going to have to go when he's out, and then what? Then what's.... what's going to happen? So, as I mean, he can go. He comes here. He's come here a couple of times to visit me. Ahmm, he can use his urinal anywhere that he goes, but if he has to go to the toilet, they're not....they're not working with him on the physical end of like stand- pivoting him....where if they were doing that....That's something that I'm constantly trying to get them to do because then he could go into a bathroom, a handicap bathroom somewhere, you know, if he were out somewhere. He wouldn't have to worry about that. But it's getting him from his chair to-to the toilet. So that's an issue...” (Glinda, Family Caregiver).

To be able to move out of the long-term care facilities and obtain services in the community, individuals needed to have essential documentation and identification.

Having been in the long-term care facility for years, some have either misplaced or lost such documents and need to have them replaced. However, because of their poor functional ability, they are unable to do so independently or go with the transition coordinators. This often poses problems because some of these documents are confidential and disclosure to a second party needs some level of evidence. Going through such processes unduly delays the transition process.

“I had a woman who couldn't. She was like over 400 pounds, so I had to get a letter from the social worker to prove that she's unable to leave the nursing home.

And then, ahmm, try to renew her social security card, her, ahmm, ID card, get a birth certificate. So, I needed a lot of permission from everybody, and I ran around trying to get all that together.” (Luz Marie, Transition Coordinator)

### **Institutionalization Effects**

Having lived in the long-term facility for a long time, individuals learn to become more dependent on others and have a learned behavior of expecting to be helped. Because of this, once they transition into the community, they are reluctant to do anything for themselves and expect the residential home staff to help them. This can be a problem, since the expectation at most of the residential group home programs is to have them be more independent, which is often very challenging for them, and thus impeding their full participation in the community.

“Ahmm, because a lot of the clients I have seen anyways.... because they have been in the nursing home and they've kind of learned this.... learned helplessness, they don't wanna do anything, you know...” (Alyssa, Occupational Therapist)

“We do because nursing homes do a lot of.... Our philosophy in the programs that I open are.... we do with and not for. So, we want to challenge them to do as much as they possibly can for themselves. At first, it's typically challenging for them because they've never been challenged to dress themselves or put toothpaste on a tooth brush.... some of the common, just the little things that we take for granted. They've not had that for two or three years, while being in the nursing home. It was always done for them.” (Joe Smith, Residential Program Director)

### **Inappropriate Behaviors**

Having inappropriate behaviors was one of the barriers participants described in this study. Individuals with brain injuries can be impulsive, can sometimes be physically aggressive, and may exhibit sexually inappropriate behaviors. These behaviors often cause safety risks to staff and other residents in the house. To manage such behaviors,

medical providers sometimes over medicate these individuals which in turn can cause a decline in their functional ability. This can be problematic as it causes frustration for the families as well.

“There was one guy here who just he had a TBI, and he was still recovering, and he was still recovering mentally and part of his recovery once he became more and more violent I imagine his family was pretty upset about you to know what happened in his situation because he...you know took some steps back because he was probably going to need to be chemically restrained for a while- while he went through that stage of recovery.” (Chossey, Family Caregiver)

“And, ahmm, he.... he was a handful. They'd find him where he wasn't supposed to be, or people in his room or, you know. They weren't adapted for somebody that was so physical. He's hyperactive, so he constantly had to be, you know, one on one almost, otherwise he would disrupt things. He got all depressed, and then he started getting angry, and they started medicating him more. Yeah, he'll throw things or pound and hits his head. You know, he's like a big kid. Yeah, he has problems. He's always been like that. When he's lucid, he's a pain in the neck. He does.... he's very aggressive, you know, and he's just.... he's like a big kid. Ahhm, he was very alert. They keep changing his meds and....and they keep putting them stronger, and he's just been...he couldn't even talk. He was just out of it. His eyes were glazed. He couldn't sit up. I had to prop him in pillows.” (Mary, Family Caregiver)

Despite these behaviors, staff was often able to set boundaries and manage some of these behaviors, and some residents did show improvements.

“He was really, really, hard on the staff. Very degrading to them. Making racial comments. Most of the staff were from different countries, and he was very ignorant of them.... you know, very rude. You know, calling them names. And we had to say no, this is not okay. These people don't work for you; they work for an agency. And he, you know, he could make sexualize comments at times, which he had in the nursing home. But he.... he's made progress.” (Antonia, DDS Service Coordinator)

### **Family and Guardian Involvement**

Family members tend to be strong advocates for their loved ones and sometimes staff perceived their involvement as an impediment. Their strong desire to have their

loved one move into the community can cloud their assessment of the capabilities of their family member. Such bias is sometimes perceived by the professional caregivers as negatively influencing the process. For example, one caregiver attributed an individual's eligibility into the program as a result of such bias, even though she felt the individual was not appropriate for transitioning to the community due to his complex health issues.

“So, the family member was there, and we did think was answering most of the questions. And from their perspective that they were giving to the eligibility person, he can do these things. In reality, that's not really how he is.... and they deemed he was eligible based probably more on her report than anything. She, as a family member.... I think that of course.... she wants to see him move to the community.” (Sue Smith, DDS Service Coordinator)

“We have other family members who are just really such strong advocates for their individuals that sometimes.... I don't wanna say they impede the rehabilitation process, but they tend to be kinda overly involved and wanna know every step of the process and might not necessarily understand the process as much as we can explain. You know, why certain things are important. They can really kind of impede that, so I definitely have seen both ends of the spectrum where there's too much involvement.” (Sue White, DDS Service Coordinator)

On the other hand, some family members are not as involved, and sometimes that can be a problem if they happen to be their legal guardians as well. This is because it becomes difficult to get them to come in to sign consents and other paperwork needed to move the process forward. This barrier is most significant when the guardians are court-appointed, since they have a minimal relationship with the clients and often seem not to care as much. To get around some of these issues, consents, for example, are signed very early on in the process to minimize any future delays.

“Some can't. Some of them are not involved in that aspect. We have guardians who (laughs 47:16) was supposed to show up to transition meetings and everything else and doesn't show up. Ahmm, they're not responsive, and usually, those are the court- appointed. We have a lot of court-appointed guardians, so we don't have...tend to have a good rapport or even try...even have an established relationship with them. So, it can be challenging for the providers. Ahmm, if it's a family member, they're generally more responsive and more involved. Ahmm, but

there are times that they're not and we have that barrier where they need to sign things, and we can't get them signed and it may.... especially with consents but usually, the consents are signed before us coming in, which is good.” (Cassandra, DDS Service Coordinator)

### **Having Negative Perceptions of the Individual**

Transitioning individuals from long-term care facilities to the community involves lots of information gathering and sharing among different individuals and entities. Information about the individuals is often obtained from assessment reports prepared by other entities involved in the transition process, as well as documentation from their medical records and staff interviews. Such documentation sometimes gives an adverse representation of the individuals who are looking to be moved. This sometimes creates negative perceptions of the individual, which sometimes jeopardizes their chance of transitioning to the community. This can also erode trust among collaborating agencies, which is a barrier. One professional caregiver shared her experience where she felt such perceptions created an undue bias against individuals with substance use and extensive criminal histories. She felt strongly that a person does not have to be defined by their past.

“In our office, we have several cases where perception has had a negative impact on how we are transitioning the person. For instance, I had a case just recently. We're in the middle of the transition. At the second meeting, the agency came back and was digging through files, and then they sent us this beautifully written e-mail that says we have some concerns that may derail the move date that's coming up in two weeks. Come to find out, reading through his files that was at nursing home, they found out he drunk in the last six months. They found out that he has a very lengthy criminal history. What does it really mean to manage a person with substance abuse and long criminal history? I've come to realize that sometimes chartings can sometimes change a person's perception and absolutely derail the process, because everyone is coming from a negative point of view.” (Tina Marie, DDS Service Coordinator)



## **Process Barriers**

Process barriers are the obstacles encountered during the transitioning process as a result of suboptimal procedural strategies. Dysfunctional communication was found as the only, but major, process barrier described by participants in this study.

### **Dysfunctional Communication**

Dysfunctional communication among and between members of the transition team was rampant throughout this study. This dysfunction obstructs the process of moving an individual out of long-term care facility to the community. For example, to be determined eligible for the waiver program, specific pertinent information is needed to make the final decision on eligibility. Missing information gets communicated through a letter to the individual's guardian. However, when there is a breakdown in communication between guardian and social worker, information is not shared, and the individual ends up getting denied. Sometimes, misunderstanding of the shared information by recipients lead to dysfunctional communication. Again, this can cause undue delays in the process, or the denial of an individual's application to the waiver program.

“You know, we'll get notified that.... oh well, they not going to get approved or they didn't get approved because you didn't submit the SACA. Sometimes we don't even.... I don't know, if maybe the person's guardian did get it, but he wasn't one that would frequent his mail or pass that on, you know. I hate to have somebody's application get held up because we didn't know that we were supposed to submit something.... when I received the denial, it was just...it was denied for verifications and it didn't say what it was.... what they were denied for. I was assuming it was financial because at that time we were having a financial Mass Health issue on our end, as well for this particular resident” (Rose Quartz, Facility Social Worker).

Dysfunctional communication impedes the sharing of information during the transition process. When information is not adequately shared, decision making is limited, which may sometimes result in making inappropriate or poor referrals to the program. This may sometimes result in the individual's application being denied. For example, study shows a dysfunctional communication between transition coordinators or option counselors and facility social workers. They seem not to communicate with each other when decisions are being made as to which facility resident should apply for the waivers. Therefore, the social workers are taken by surprise sometimes as to who may be on their list for referrals. Such failure to share information may sometimes lead to inappropriate referrals to the program. They may sign up someone who is too medically complex to transition because they failed to communicate their intent to the facility social workers, who may know the applicant's current status.

“A lot of times I'll... some of the coordinators will come in, and they'll already have people listed as a name that they want to talk to and I...there's no problem if the person is there and they wanna talk to them.... that's fine. But it's.... sometimes its people that, ahmm, either I know haven't even been stable here with 24-hour nursing care, so I don't necessarily consider them going back to the community. At that point they need to have that stability first if they are going to the hospital, you know, a couple of times every month. I feel like that's...maybe it's not time to think about discharge to the community.” (Rose Quartz, Facility Social Worker).

Sometimes when option counselors go to long-term care facilities and sign up applicants for the program, they go directly to seek out the person without communicating with the facility social workers. This can be a problem, since some residents have invoked healthcare proxies and cannot make such decisions for themselves. Thus, not communicating with the social worker first can result in obtaining

inaccurate information, thereby making inappropriate referrals. They also stand the risk of violating the legal rights of the health care proxies.

“Come in to talk to me first, because now you've just talked to someone else who.... came to me to basically say she wants to go home, but you didn't know the circumstances. You don't know the situation. You're just going off .... you don't know that they're invoked. You don't know that what they're saying isn't accurate. So, I basically told them you can call her sister now, and tell her sister why she's going to be asking about this program” (Rickie, Facility Social Worker).

The dysfunctional communication between transition entities, cuts across the state. It was interesting to note that concerns raised by a facility social worker in Middleboro, that options counselors do not communicate before contacting potential applicants were similar to those brought up by an options counselor in Lawrence MA. The latter stated that it was the social workers who were never available to talk to and went farther to suggest that they were themselves obstacles to the process. It was evident that such dysfunctional communication had resulted in some animosity among entities.

“But she was making herself an obstacle because I had options counselors that were like, I'm not going there because I can't get in touch with her and then.... I said, you get the referral, you leave a voicemail, because you know she's not going to answer the phone, and you say, I got the referral for Mr. Smith. I'm gonna come on Tuesday the 15th at 2 o'clock. If you're there, you're there. If you're not, I'm going to see Mr. Smith still. And she was never there, but then she would call and complain. She would give people a hard time, so she was a problem for us. I had to call the administrator because I said, I know she means well when she wants to be involved, I said, but she's making herself an obstacle. I said we don't work for her. We work for the consumer. We're here for the consumer. We wanna work with her, as you know, as a team approach. But she's making herself an obstacle.” (Summer, Transition Coordinator).

There were reports of breakdowns in communication within the process in other instances as well. A failure in communication impedes information flow and sometimes may put the safety of the individual at risk. For example, an individuals' treatment

modalities are sometimes not followed or entirely missed due to such dysfunctional communication among staff.

“He was almost flat, and you know, he was eating a peanut butter sandwich. Nope! I almost lost it! I got in my car.... I said, first of all, I don’t know about the staffing team and who’s here and who’s not here. But this communication should have been passed DOWN that he’s not to be eating and he knows this. And I said, you know, so and so, you know this, you could choke! He’s like “I haven’t choked yet,” and I said YET is the key” (Antonia, DDS Service Coordinator)

“Ahmm, because of the communication within houses, sometimes it comes down to the fact that we have standing appointments on Tuesdays. But, you know, the house manager didn't relay that to the daily staff that day and they're out shopping. So, we've now shown up to the house and there are no residents there. Ahmm, so those are kind of my viewpoints, ahmm, as standing out, you know. They are in the houses more than I am but that, I think, is what I hear the most from everyone” (Elizabeth Hapgood, Rehabilitation Director)

During the planning phase of the transitioning process, all the entities involved communicate a lot to ensure that they know their roles and the expectation for them to complete all assigned tasks. Often there is a breakdown in communication and transitions are unable to proceed as critical information may be missed, resulting in an unaccomplished task.

“I called the nurse and I'm, like, is everything ready to discharge so and so? What do you mean? No one told us anything ... And then I get an email from the social worker that she's out and she hasn't been able to get in touch with the nurse. So, there was no communication and....and they have new personnel there.” (Luz Marie, Transition Coordinator)

“Yeah. I think.... I feel like most of the area.... communication with them.... when you do the transition, this communication with the nursing homes can be a big challenge. So, the challenge can be that communication between us and the nursing home, when we’re trying to get the transition going.” (Ubda, DDS Service Coordinator)

Sometimes such breakdown in communication leads to cancellation of transition meetings, which unduly delays the transition process.

“Last week I had four transition meetings scheduled. Out of those four transition meetings, only one of them happened because you show up at the facility, nobody knows you are coming, they claim you don’t know that you are coming, they.... they don’t have somebody from rehab who can speak to the medical equipment piece....” (Sue White, DDS Service Coordinator)

Finally, communication may be dysfunctional if there are inaccuracies in the information shared. Sometimes individuals within an organization give contradictory information to the transition coordinators. Such errors can be problematic during planning and ordering of equipment and placement of services during the transition process.

“The other obstacle we have is the floor nurse knows the people better than the DON [laughter 32:19]. So, you.... there’s been times that I will go and get an update from B--- and get the exact information that I need, and the Neurorestorative or provider will go and talk to D..., who is the DON, and get very different information, and it’s not accurate. Ahhm, so [laughter 32:35] that’s been a barrier and a conflict.” (Cassandra, DDS Service Coordinator)

### **Systems and Organizational Barriers**

These were factors that directly or indirectly obstructed the processes involved in managing the transitioning of individuals with TBI from long-term care. These factors were due to the organizational policies, practices, and delivery of services.

#### **System Barriers**

System barriers refer to factors arising from a larger organizational body, i.e., The Executive Office of Health and Human Services, who oversee the development and implementation of Medicaid Waiver programs within the Commonwealth of Massachusetts through its Mass Health Offices. Factors associated with their policies and services that directly or indirectly obstruct the transitioning process will be described in

this section. The system barriers include policy, bureaucracy, strict waiver regulations, inaccessibility of services, and insurance requirements.

### **Negative Policy Impact on Long Term Care Facilities**

As part of the Medicaid waiver program, professionals go out to long-term care facilities to outreach to residents who meet set criteria to apply for the program. Eligibility is then determined based on set criteria, which often favors individuals with higher level of functioning who can be safely served in the community. The process can be selective and often may have unintended repercussion on the long-term care industry.

“I think actually... I really think that their ABI waiver program was part of the reason why Middleboro Skilled Care had to close because of the ?...This is honestly, they cherry pick the patients that were earning them the most money for the least amount of work and pull them into their program and the people that were left were completely paralyzed from the neck down on tube feeding or requiring you know four hundred thousand dollars’ worth of care a year and that's not what their insurance was bringing in or their disability was bringing in. Whereas somebody like my dad who brings in that same amount of money uses a hundred thousand a year for his care. I really think that, that cherry-picking ability to take somebody like my dad, not somebody who is paralyzed from the neck down made a huge financial impact on the facility that he was in.” (Chossey, DDS Service Coordinator)

### **System Bureaucracy**

Another system factor that individuals identified was having to deal with bureaucracy. Bureaucracy is defined here as an organization designed to accomplish large-scale administrative tasks by systematically coordinating the work of many individuals. Such a system of administration is characterized by a clear hierarchy of authority, rigid division of labor, written and inflexible rules, regulations and procedures, and impersonal relationships (Blau, P. M.,1956). Dealing with such a system can be

frustrating, as it usually involves going through different people in different departments within the organization and having to complete lots of paperwork. Both professional and family caregivers described their experiences of having to work with such bureaucracy associated with the Medicaid waiver program. One participant felt that working with the waiver program was synonymous with her experience of working with the mental health system in taking care of her granddaughter and mother. In both instances, she had to complete lots of paperwork. Having to deal with bureaucracy may result in undue delays and impede the transition process.

“We had to go through all kinds of paperwork and he did....and I didn't because, I knew the process, you know. I've been working with the system for 25-30 years. I had a schizophrenic granddaughter I took care of and the crazy mother, unfortunately. She had mental problems severely, so, I took care of her a lot, off and on. It is a whole process that has to go through. All these records have to be transferred, and then they have to see if they can take him.” (Mary, Family Caregiver)

“You're not going to get your power chair for a while....it takes.... it's a whole.... another bureaucratic thing to go through.... the insurance and get it built. That will come definitely, but it's just a longer process.” (Antonia, DDS Service Coordinator)

### **Strict Waiver Requirements**

The Medicaid waiver program has set criteria and policies. For example, to be in the Acquired Brain Injury (ABI) waiver program, you have to have lived in a long-term care facility or a chronic or rehabilitation hospital for at least 90 days. Also, you should have experienced an acquired brain injury at age 22 or older. An acquired brain injury can result from a stroke, brain trauma, infection of the brain (such as encephalitis), brain tumor, or anoxia (lack of oxygen), etc. One also must meet set clinical requirements and need a waiver service. Furthermore, an individual must meet specific financial

requirements to qualify for Mass Health (Commonwealth of Massachusetts, 2018).

Failure to comply with these restrictions may result in a denial of the program and a missed opportunity to transition to the community for some individuals. This was of concern to some study participants and perceived as a barrier, as they sometimes felt the determination of eligibility was confusing.

“No, I wouldn’t.... I think sometimes the process can like.... well, that they have to be someplace in 90 days is difficult. I wish that they didn’t have to wait for 90 days. But that’s the regulation. Nothing that.... I guess you can really change about federal regulation. But I think sometimes the whole, like, clinical review part sometimes can be a little.... a little confusing for the social worker, as to why some people get accepted and others don’t. That is challenging. Or why some people are felt to be safely managed, and others aren’t. I just.... I sometimes don’t see the.... I don’t see the rhyme or reasons sometimes. I don’t understand it. I wish it came with a reason letter with it.” (Rose Quartz, Facility Social Worker).

Another issue considered a barrier was the strict waiver regulations. The waiver assigns and adheres to a limited number of slots each fiscal year. Once slots are filled up, individuals have to wait for a year to reapply. Not only does this cause emotional distress, but it impedes the transitioning of an individual to the community.

“A couple of times when we did get an application, there was already a wait, and some people missed that qualifying cut. There weren’t enough slots. So, then we had to wait again for the next year to reapply to do that. I had to wait another year, and that was sad because there is no other references or referrals that I can make for that person. So, I had to wait another 8 to 9 months, and I filled out the application in January. And then as soon as like February hit, I just sent in because Western Mass told me just send it in early. And we were able to get him on before I had left that building.” (Nicole, Facility Social Worker)

### **Insurance Requirement**

To transition individuals with TBI out of the long-term care facility to the community requires purchasing durable medical equipment as well as setting up medical services in the community like specialist appointments, therapy services, etc. Health



insurance providers administer such services. Participants described that dealing with insurance providers can sometimes be problematic because they often had set requirements that had to be met. These insurance policies often posed some challenges and were barriers to the transition process.

“Ahmm, as I'm learning, you get one thing from the insurance company, and that kinda gives you.... Ahmm, if you've just gotten into a wheelchair, ahmm, Medicare doesn't want to.... Medicare is not approving a walker to practice standing.” (Isadora, Occupational Therapist)

“Ahmm, I don't know if they're doing it right now. That's always the issue, because Mass Health will only pay for so many visits. And I believe the program is supposed to pick it up, but then there was a problem with finding a place that would take him. Well, I'm always told that it's like, an insurance thing, or they can't find... that can work with him, in the house. So, they want him to go somewhere where there's equipment, but then it's always an issue of Mass Health covering it.” (Glinda, Family Caregiver)

“Ahmm, not the hospital beds.... sometimes the hospital beds because the person needs it but doesn't have a qualifying diagnosis, so the insurance will deny them. Ahmm, so certain diagnoses qualify for a hospital bed or purchase of a shower chair [laughter].” (Cassandra, DDS Service Coordinator)

To ensure a successful transitioning, professionals need to plan and make sure that all equipment, including the bed, is in place before discharge. Therefore, timing is of the essence. Yet this is not always assured, since insurances have specific time frame requirements which can cause impediments to the process. For example, insurances will not pay for a bed to be delivered two days in an advance to the home because they are paying for the use of the bed in the nursing home.

“Well, it's, you know, it's so challenging because we like to have the bed there like at least two days before a person moves so the room can be set up when somebody's coming in. But a lot of times with insurance, if they're already placed somewhere that is technically they're paying for a bed, they won't pay for another bed until the day they move.” (Sue White, DDS Service Coordinator)

“Because sometimes there are all kinds of tricky things with ordering things under insurance, you know. Certain things can only be ordered the day before discharge, and you have to be present for delivery, and it can only be that person present. There are all weird, tricky things with insurances. It can’t be ordered up to 48 hours before the time of discharge, and each piece of equipment is different with its ordering specification.” (Ava, Facility Social Worker)

### **Availability and Accessibility of Services**

The ABI and MFP Medicaid waivers in the state of Massachusetts provide many services to program participants including day program services, peer supports, residential group homes, physical, occupational and speech therapies, among others. Despite this, participants described that such services are not always available or accessible for various reasons, including geographical location, the number of group homes built, problems finding appropriate service providers, and lack of proper services

**Geographical Location.** The geographical locations of residential group homes where participants reside can be a barrier. This is because many of the houses are located in suburban or rural areas where it is more quiet and serene and less stimulating for the individuals with TBI. Though appropriate, it has some drawbacks, as providers often do not have the resources or staffing to provide services in those areas.

“And then the other, I guess, challenge in the same aspect would be based on where I work, which is typically the North side of Worcester.... that’s a lot more rural in that.... like the Leominster area just around there. There are fewer people up there and so there are fewer options for day programs. Whereas, if you’re looking at Springfield here, Boston area, Worcester.... there are many options that someone can tour, which is good.... where there is not much out there. That can be a challenge.” (Rudy, DDS Service Coordinator)

“So, believe it or not, so I cover the Worcester area....and I feel that in the Worcester area, we struggle more than the Springfield area does concerning trying to find providers” (Sue White, DDS Service Coordinator)

“In my areas.... for me is the Pittsfield area.... the Berkshires. The Berkshires. There are not a lot of services compared to what people will get here in terms of transportation, a psychiatrist. A lot of things over there is lesser than here. Yeah, enrollment for the new patient. It can be a very big challenge, especially for my area over there. Even primary care doctors can be a challenge.” (Ubda, DDS Service Coordinator)

Sometimes providers do not access these areas because it is not feasible or not worth it for them as an organization due to the low reimbursement rates offered them by the state.

“.... the available hours that people had.... servicing a house out in Pittsfield or something else, was not feasible as far as staffing, timing, or anything else. And in order for us to service a house that is that far away from any staff.... I would need there to be a cluster so not just one house, but maybe even 2 or 3 houses within close proximity to each other.... We reimburse the staff for the travel time, but we do not get that time reimbursed from the program. So, if my staff is driving an hour and a half to two hours to see a house full of clients, the cost financially for us is not viable to travel out that far. So, now that I have staff that is closer, if there was a cluster of three group homes within a 5-mile radius of each other, it could possibly be feasible to, ahmm, service that area. However, the reimbursement rate.... the waiver reimbursement allowed....it is not something that is sustainable from an organizational standpoint.” (Elizabeth Hapgood, Rehabilitation Director).

**Lack of Appropriate Services.** In areas where services are readily available, the issue for participants was that they were often not appropriate and did not necessarily meet the needs of their clients. For example, many felt that many of the existing day programs were either geared towards the older adult population or individuals with intellectual and developmental disorders and was not suited for individuals with brain injuries. They found this to be a barrier because individuals with TBI or other brain injuries were reluctant to use the services, which impeded their community reintegration.

“For daytime, for example, like we have somebody who is 30 years old.... they normally go to an adult day to get out of the house with somebody who's.... most

of them are 80 years old. Not 80, but you know what I'm saying. It's for the elderly." (Luz Marie, Transition Coordinator)

".... they're very intelligent, and I sometimes think, some of the day program providers that we use come from the traditional services of working with folks with intellectual disability and they're not gearing some of their programings in a way that the individual feels like it is at their level. They kind of feel like it's that more of a child-like level. And so, that that's how.... I hear that probably a lot more than any complaint is they don't like the day programming because it doesn't meet them at their level." (Sue Smith, DDS Service Coordinator)

"Some don't want to do the day program, which is usual. But they say a lot of people go to day program, but most of our people.... they go there for one or two, three days, and it doesn't work for them, so they just do something different." (Ubda, DDS Service Coordinator)

**Number of Group Homes being Built.** Having enough group homes available is critical to program success and sustainability. Without having safe and accessible homes, individuals cannot transition out of the long-term care facilities to the community. Study participants described that finding providers to build these homes, going through towns and cities red tape, as well as the real estate market conditions, can make it almost impossible to develop or get houses ready and on time for transitions. This can be problematic as it causes undue stress to individuals with TBI and their families. This slows down the transition process significantly according to some study participants.

"It's' just unfortunate that there aren't enough houses being built or providers building houses to accommodate the number of people in the SNFs that need to be relocated. Right now, it's a sellers' market, but so many people are looking to buy homes that they're competing with so many people right now to buy land for these homes. I know one of the providers that I was affiliated with.... ahmm, we were buying homes just to tear them down, so we could have the property to build new homes. Waiting for homes to be built, ahmm to me, is what's slowing the process. We have so many people on deck waiting for a house to go into but there is not a house to go in to, that's the problem. It's taking, you know, a good year for homes to be built, so it's, it's, ...." (Chip, DDS Service Coordinator)

The problem of finding houses to buy or land to develop is much worse in metropolitan areas like Boston because, they are built with little land available for development, and have a high cost of living.

“We....it tends to be a little longer and it is unfortunate in that respect, but I think that a lot of other regions ...and this is kind of what we hear from different service coordinators, is the housing piece. In the Boston metro area, it is a huge hindrance to us in the transition. So, unfortunately, that’s part of that transition.” (Jessica, DDS Service Coordinator)

“So, what's been happening in our region is because this is the metro region and the cost of living in this area is exceptionally high, we have a lot of folks in nursing facilities on our caseload who really want to live in Cambridge, Belmont, Waltham, Watertown, you know, within that 128-belt. So, it's been difficult for some of the providers to find either land so that they can build a group home or rehab a home.” (Sue Smith, DDS Service Coordinator)

**Finding Service Providers.** Finally, the reason why services are not readily available or accessed is because of the difficulty in finding organizations who are ready to provide such services. Reimbursement rates are not always attractive and sometimes finding specialized professionals is difficult.

“We don’t have any approved provider who can do the PT, OT, or Speech therapy in that Berkshire area. I try the MAB, send the referral. They say they cannot go that far west. So, it’s kind of challenging. I still haven’t been able to secure or get anybody who could do.... I just did an intake on Friday for one of my guys, after being in the house for over a year. Eventually, he says, you know, I can go to a day program. And he needed it. We did PT at home, OT, but eventually insurance phased out and then I couldn’t get a provider through the waiver.” (Ubda, DDS Service Coordinator)

“Yep, but some houses don’t have nursing 24 hours or 16 hours in a day, you know, so, it’s challenging in trying to match them with the right provider to meet those needs. Depends on the person.... it’s all very challenging.... Ahmm, but he.... the nursing requirement that came out of here is 24-hour nursing, and right now no provider can provide 24-hour nursing.” (Cassandra, DDS Service Coordinator)

“Despite program effectiveness, there were some setbacks identified, particularly finding providers/vendors under the waivers to provide needed services. The problem of vendors dropping off the waiver came up. Probably because the reimbursement rate is not beneficial for them. Hmmm.” (Field Notes)

### **Organizational Barriers**

Organizational barriers were private or public factors specific to an organization that were associated with the Medicaid waiver program within the state. These factors arise because of the organization’s philosophy, policies, and practices and can obstruct a smooth transition of individuals with TBI from long-term care facilities to the community. Some of the factors identified include staffing issues, lack of organizational commitment to process, and dealing with different organizations.

### **Staffing Issues**

These are factors affecting staff (employees) within the organization that impeded the process of transitioning from a long-term care facility to the community. They include staff turnover, staff workload, staff training and knowledge, and staff attitudes.

**Staff Turnover.** Study participants brought up several staffing issues within organizations that work directly with the waiver programs (particularly the long-term care nursing facilities and the residential group homes) that hindered the process of transitioning. Many of these organizations had high staff turnover and that impacted the process, as it was often difficult to ensure continuity with the transition planning process

or with the plan of care. This was because new individuals had to be retrained which sometimes took time.

“Many of these houses, while the staff have hearts of gold and mean well.... ahmm, the staff turnover is so high, that as soon as you get staff trained, they're gone. Ahmm, and now you're retraining staff for something that you should be 5 steps ahead, but now you're 2 steps back again.... ahmm, because it's all new staff and all new education.” (Elizabeth Hapgood, Rehabilitation Director)

“No, constant change, constant. I've even had some staff tell me stuff and the next time I went there they were gone.” (Mary, Family Caregiver)

“In a nursing home with, I think, her floor she had 50, 60 people. A lot of call-outs.... a lot of staff turnover over there, so she was working very, very hard.” (Cassandra, DDS Service Coordinator)

**Staff Workload.** In addition to the issue of turnover among staff, the staff in many of these organizations (primarily the long-term care facilities) have very heavy workloads and find it difficult to accommodate any additional work. The transitioning process is complicated and involves lots of preparation and coordination, which unfortunately may be perceived by staff at these facilities as extra work.

“Ahh! So, a lot of the barriers come from the nursing homes themselves and them being willing. They're overworked. They have a lot of people.... ahmm, a lot of issues....” (Cassandra, DDS Service Coordinator)

“There's not enough staff in facilities. There's not enough time in the day. There are not enough social workers to go around. Ahmm, you know, if you have a building that has let's say four or five people transitioning to the community, you need a social worker just for that. Trying to get a physician's statement or a physician's form filled out, is not easy and that.... the DDS team needs to understand that, and they need to give at least a month to two months' notice.” (Ricky, Facility Social Worker)

“Yeah, it's a long.... it's a.... they do give you time, they do but, considering, ahmm, sometimes facility life in here.... if you're dealing with, ahmm, I mean my caseload right now is a hundred residents right now. So, to get that detailed with someone.... you get others, and you're trying to deal with people that are just, you know, regular short-term coming in and its.... its time-consuming at times.” (Rose Quartz, Facility Social Worker)

“And just by reviewing everything that we’ve talked about, how can a social worker do all of this for a consumer who is in a nursing home? Impossible. She has a caseload.” (Luz Marie, Transition Coordinator)

Their perception of the process as additional work sometimes makes them come off as being uncooperative and indifferent to their role in the broader transition process.

This has been a huge barrier to the process, as team members have lost the trust to rely on them to successfully deliver on their assigned tasks in the process.

“She shared her frustration working with nursing facilities. She complains about the lack of cooperation, the lack of follow through with their piece of the process. And high turnover among the social workers makes the process very daunting” (Field Notes)

“You have people at the O...d that they hide. You know, you have to go find them. They don't wanna....and my opinion.... they don't want to be bothered. They don't.... they don't wanna deal with it. That's just, that's.... that's been my experience. (Summer, Transition Coordinator)

“So, things like that, and not only once they get.... but let's get to a point when they get discharged. So, we've been having a problem with one particular nursing home where the social worker drops the ball, and we have to take over everything.” (Luz Marie, Transition Coordinator)

“So, it depends on where they are at, what nursing facility, what the.... who the social worker is. It's all a crap shoot. It's all a crap shoot because, you know, some things we have to have them put in 30 days prior....no, earlier than 30 days prior for like equipment needs, for like a bed, a Hoyer lift or.... Some will just say, oh, it got denied. I mean, they said they put in, who's to say they didn't and it got denied. Then why did it get denied. This person needs it and then we have to order it through the waiver, which is fine.” (Antonia, DDS Service Coordinator)

This problem was not only particular to the long-term care facilities, but it also was noted in some residential home settings. Staff in the residential homes are more inclined to do their daily routine tasks related to the general upkeep of the house and direct care of the residents. They sometimes attach little regard to functions outside of



their daily tasks. For example, having the individual practice their therapy exercises or use recommended adaptive equipment were not followed through by staff.

“And the other part is, often I think the staff in these situations, they get lists of tasks to accomplish each day that is more related to the general upkeep of the house and the care and the health.... health.... ahmm, cleanliness of the individual. Adding therapy exercises into that doesn't always make it onto the list of things to do.” (Elizabeth Hapgood, Rehabilitation Director)

“So, you're getting this equipment.... you practice with it? They're like, “oh yeah,” we can use it. And then you talk to them.... nope we've never used it.” (Alyssa, Occupational Therapist)

**Staff Training and Knowledge.** Participants in this study also perceived staff in some residential group homes and nursing facilities as lacking the required training and knowledge of the process to adequately provide direct care safely to the individual who transitioned to the residential home setting. This often led to frustration either with family caregivers or members of the transition team.

“He had texted me and said that they would.... weren't putting him to bed. I said, what do you mean they're not putting you to bed? And he said that, ahmm, he kept asking them to put him to bed, but nobody that was working that night knew how to put him to bed. Well, he uses the Sara lift, but they didn't know how to use it, and he didn't end up getting put in bed until midnight. I was on the phone with L...a.... this cannot happen again. Cannot have people working in that house that are not trained to work with J---a. So that was a....that's a problem. If they're going to work in that house, they need to know how to take care of my son.” (Glinda, Family Caregiver)

“No, they couldn't use the machine. Nobody was trained. But, they told me that they were. When he moved in there, they said he'd be, you know, you don't have to worry about him we've got all these machines. And they have all the machines there, but nobody is trained, and they dropped him. And from there it was downhill. That was in December.” (Mary, Family Caregiver)

**Staff Attitude.** Participants also indicated that staff attitude could be a significant barrier. To successfully transition an individual from the long-term care facility to the

community, you need full cooperation from the staff at the long-term care facilities.

Participants in this study commonly felt that staff attitude, particularly towards program, was sometimes negative. For example, they are reluctant to allow service coordinators access to take part in the individual's care plan meetings or access to pertinent information needed to transition the individual successfully. They were sometimes discourteous.

"They are not open to, like give that information freely. Like, they have what is called care plan meetings recorded. We will go in and say, please invite us to these care-plan meetings, so it is a way to get updates. What they are doing in the facilities, if there have been any medical changes anything, and they do not invite us. But it will be a great way to communicate and for us to communicate to them the progress of what is going on in the community. That is, the house is being built, and you know, nope! Nope! It is not a collaborative effort." (Sue White, DDS Service Coordinator)

"This particular social worker.... I actually had to consult with one of our social workers here. She went out to one of the meetings. We've had other people dealing with her and actually somebody.... I think it was in the mass rehab I think, also came out and they all kind of had the same consensus that this woman is just.... there is no good way to put it, but kind of crazy. She's just, I don't know, some people you know, maybe shouldn't be in the field of working with people.... and I think she's just one of those people." (Sue Smith, DDS Service Coordinator)

The attitude of the social workers at the long-term care facilities caused frustration and even anger among some professional caregivers, but others were also understanding of such attitudes and tried to work with them despite their negative attitudes.

".... because this is not their everyday role as a social worker at the skilled nursing facility. So, I understand their attitudes, when sporadically, we're just calling and saying transition meeting, transition meeting! We're pulling five out of hundreds in your home to say.... we need you to sit here and manage this one person. Like you have time to.... like you have time to do this for two hours with us. They don't, and that's why they go crazy when they see us, and it's like, we get it." (Tina Marie, DDS Service Coordinator)

It should also be noted that not all social workers had these negative attitudes, some were very helpful and cooperative and made time out of their busy schedules to help foster these transitions.

“Some of them, you could see that they're busy, but they understood that they had a role to play. So, when I came in and said ABI waivers, like they dropped their papers and said yeah, what's going on, you know, who are you looking for? Whoa, it's like, wow! You do exist. There are good social workers that get it....”  
(Tina Marie, DDS Service Coordinator)

### **Organizational Management and Policies.**

Different organizations are contracted with the state as residential group home providers. These organizations have their policies and styles of management which influences how each house is run. Every house is operated independently of each other and norms and culture in each of the homes may differ based on the style of management that exists in the house. Outside agencies find it difficult to work with all the different houses due to inconsistencies in management styles.

“I think, ahmm, I see a lot like from the top down with the program manager, ahmm, and the program director. They're.... they all have different roles in different houses and different programs within the same program or different programs, and so there's not a hierarchy of where to go as an outsider. This person A makes the appointment in this house, but B makes the appointment in the other house, and so there isn't a continuity, and these are houses within the same program. So, in trying to figure out who does which role in different houses and then to learn that dance and to dance that dance is very difficult. Ahhm, so because it's not the same across each residential facility.” (Isadora, Occupational Therapist)

For example, some organizations prefer that all the residents in the home attend their agency owned day program during the day. Therefore, scheduling outside agencies can be a problem. They only allow therapists to come later in the day when their residents

return from these day programs. Often, the individuals with TBI come back very tired and have very little motivation to engage with the therapist, which can be a problem in meeting their set therapy goals.

“Ahmm, scheduling. That sparked my mind a little bit because many of the program directors and managers want the participants to attend their day program. They get services at that day program that are similar.... you know, that could be occupational, physical therapy, so our role is not able to go into that facility. The idea of keeping them home or coming early for our sessions is, ahmm, right up there with the top challenge of.... probably right up there with communication, you know. They are both hand in hand in terms of the difficulties. I can see within one organization differences....” (Isadora, Occupational Therapist)

### **Summary**

The process of transitioning from a long-term care facility to the community under the Medicaid waiver program is very complex. It has a lot of moving parts and involves different independent entities. This study revealed that the transitioning process is influenced by many factors, which may result in having either positive or negative outcome. This chapter described both the facilitating factors and barriers that impact the transition of individuals with TBI from long-term care facilities to residential group homes in the community. The facilitating factors were described under three main categories (individual facilitating factors, the process facilitating factors and systems and organizational facilitating factors). This chapter also explained the seven subcategories of the facilitating factors of the transitioning process (positive individual attitude to therapy, family involvement, in-depth knowledge of process, establishing a good relationship during the process, process implementation, organizational commitment to the process, and having latitude with waiver program). Finally, the four sub-sub-categories of the

facilitating factors (effective communication, effective planning strategies, effective team coordination/collaboration, and staff commitment) found in this study was presented (See Figure 28).

The barriers identified in this study were also described under three main categories (individual barriers, process barriers, and systems and organizational barriers). The fourteen subcategories of the barriers identified were also described (individual's health and functional ability, institutionalization effect, inappropriate behaviors, family/guardian involvement, negative perceptions of the individual, dysfunctional communication during process, negative policy impact on LTCF, system bureaucracy, strict waiver regulations, insurance requirements and the availability and accessibility of services, staffing issues and organizational management, and policies). And the ten sub-sub-categories were also presented in this chapter (complex medical condition, poor functional ability, geographical location, lack of appropriate services, number of group home built, finding service providers, staff turnover, staff workload, staff training and knowledge and staff attitude). (See Figure 29).

These factors identified seemed to be interrelated, and their impact on the process was either direct or indirect. For example, communication, as described by participants, seemed to impact process implementation as well as relationship building, which in turn impacts process outcomes. The identification and understanding of these factors and how they fit into and influence the overall transition process will go a long way in helping the beneficiaries and the executors of transition programs in healthcare and beyond. Thus, further studies to fully understand the associations and correlations between factors is needed.

## **CHAPTER 9**

### **THE ROLE OF THE NURSE**

#### **Introduction**

The role of the nurse was identified as necessary in the transitioning process. Meleis, in her theory of transitions, asserts that a healthy transition depends on an effective and interactive relationship between the nurse and the patient (Meleis et al., 2000). The primary role of the nurse is to provide therapeutic interventions that seek to assess an individual's readiness for transition, assess the conditions of transition, identify patterns, and help create appropriate interventions through role supplementation necessary to achieve a healthy transition (Meleis et al., 2000). In a white paper, the Association of Rehabilitation Nurses (ARN) have called for rehab nurses to take a more visible role in managing transitions of rehabilitation patients to help improve transition outcomes, such as 30-day readmission rates (Camicia et al., 2014). Currently, the role of the nurse in transitioning individuals with TBI from a long-term care facility to the community is underreported. Therefore, this study, among others, aimed to explore the role of the nurse in the transitioning process. In this chapter, the findings on how nurses manage transitions as perceived and described by the individual with TBI, their family caregivers, and the community service providers will be reported.

#### **Nurse Role in Transitions from Long-Term Care Facility to Community**

In this study, the role of the nurse as perceived by study participant varied, and often evolved along the transition continuum and within the different entities involved in

this process. The differences were often seen within the scope of their practice as nurses in the transition process. The emphasis placed on how much involvement the nurse had in the process run along a gamut from no role to significant role. Study participants perceived minimal or no role for the nurse in the transitioning process at the long-term care level, as described by facility social workers at two ends of the state and who take a lead role in the transitioning at the long-term care end of the process.

“I sometimes even don’t invite nursing to the meeting. I may have them come in if there is a big medical component. But if we’ve already resolved that medical reason that brought them here, they don’t need to sit and listen to all the talk. We banter back and forth about individual support persons and whether or not they can read and understand their appointment schedules. That means so much in my world. It means nothing to a nurse. They don’t care about that stuff. I can go back and relay what needs to get done, and like I said, I might have the nurse come in at the beginning.... we’ll go over anything medical. She’s given her instructions or knows what she needs to do, and then I’ll excuse her to go back to the floor.” (Ava, Facility Social Worker)

“Nursing, not as much involvement. They would just come in, once we had those discharge meetings towards the end. The nurse would talk to the group for probably like 10 minutes about where he’s at medically. If he had any serious health issues, cardiac issues, or if he had wounds they’d say he’s following the wound clinic, so that’s something he’s going to need to do out in the community. So, it wasn’t very long that the nursing part had, at least for my team.” (Nicole, Facility Social Worker)

However, along the continuum and as the transition process unfolded, the nurse was perceived as a significant player and had expert roles, such as consultancy.

“If a person is very medically complicated, that’s when I also invite our DDS nurse to come with us. But usually I ask her ahead of time, what do you think, is this something you want to sit in on? And I’ll let her make that decision.” (Redsox, DDS Service Coordinator)

Despite the varied perceptions about the nurse role, nurses in this study were found to play significant roles and helped to maintain the health of the individual with TBI in the community. The significant roles the nurses performed throughout the

transitioning process included assessments, providing clinical oversight in disease management, providing education and training through consultancy, and providing direct care as indicated in Figure 30 below. The role of the nurse here occurs at both a higher or macro level within the state, and a lower level within the organization. The role as perceived and described by study participants in this study is as follows.

### **Assessments**

To transition an individual with TBI from a long-term care facility, the individual must be determined to be clinically stable in order to be safely managed in a community setting, where medical resources may be limited. Therefore, the nurse takes on a significant role to visit the long-term care facility and assess the individual for any medical risks before his/her move into the community. Assessing these risks also helps the service coordinators, as it gives them pertinent information to consider during the process of planning and setting up appropriate services in the community.

“We just, in terms of nursing, we would just go and ask to check their books to see if medically anything has changed with the person. So, we at DDS have a nurse go out with us now and then to look over charts. And, you know, I will like to say that I know medical stuff, but I don’t.... I am not a nurse... she will come and take a look at stuff. That is her specialty....and let us know if anything flags her.... that something is changed. Because we do want to know that kind of stuff.”  
(Sue White, DDS Service Coordinator)



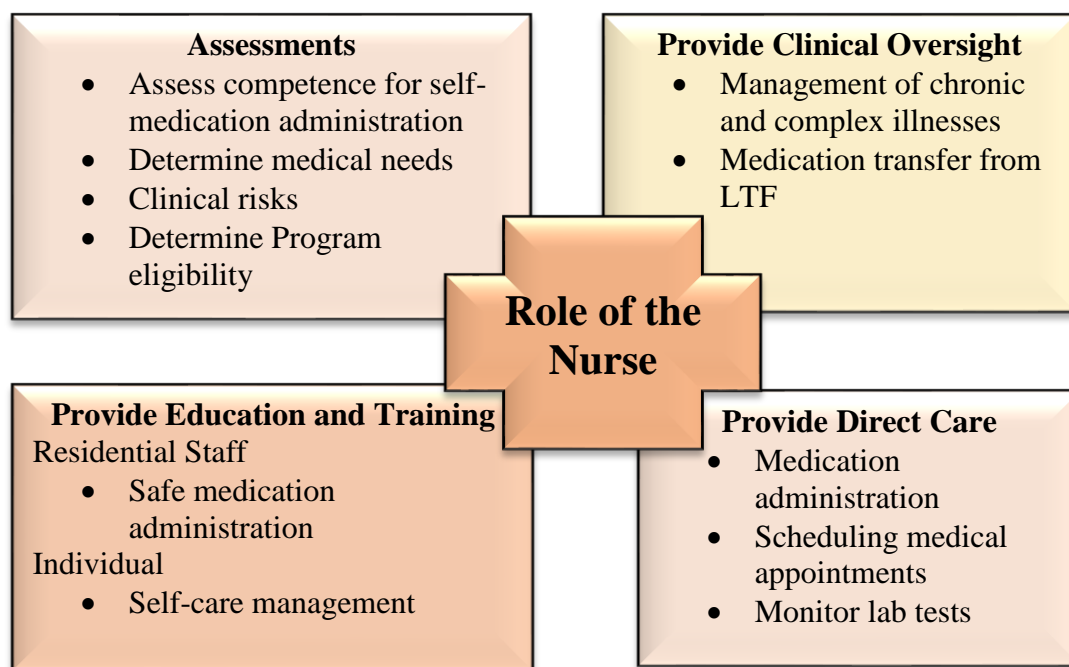


Figure 30: The role of the nurse in transitioning from long-term care facility to community

Again, at the macro level, nurses are used in determining the overall eligibility of the individual into the Medicaid waiver program. Such nurses review medical records and make site visits to interview staff and waiver applicants and assess for any risks that may preclude a safe transition to the community for the individual with TBI. One social worker explained the role of the nurse reviewer who comes in to assess applicants for program eligibility.

“The nurse reviewer that had come in [to assess the individual for eligibility] ended up calling nursing to get an update to see if there was anything new.” (Rose Quartz, Facility Social Worker)

Assessments are also done by nurses at a micro level within an organization as they manage the health of the individual. For example, the nurse at the residential group

homes assesses for self-medication to ensure that an individual is capable of self-administering his/her medications.

“We’ll do a med assessment of self-administration. So, there is a form that we kinda take a look at. Usually, Jack will do it, my second nurse, because he has the time with them at night. So, my nurse Jack will sit down, and he’ll do that self-assessment to see if they can pass their meds.” (Caitlyn, Residential Program Director)

### **Provide Clinical Oversight**

Providing clinical oversight is one of the roles nurses performed in this process, both at a macro state level and at a micro level within waiver approved organizations. At the macro level, the DDS waiver nurse provides regulatory oversight of the clinical aspects of the waiver program. His/her role is to ensure that procedures are followed. For example, the DDS nurse reviews all incident reports from participating group homes and ensures that proper protocols are in place and supported.

“Like for incident reports, that’s the other part that I... I don’t know if I talked to you about that part of the job. So, ahmm, every time that there are incident reports that come in, I am the one that looks at the incidence reports.... the reports from the homes. That comes in from the service agencies. I look at.... look at the action steps and, ahmm, and I’m the one that finalizes, you know, whether the incident was handled properly or not handled properly.” (Kandi, DDS Nurse)

Oversight at the micro level involves the residential group homes. Each home provides a minimum of 12 hours of oversight nursing. The role of the nurse in such instance is to ensure that the individual with TBI is receiving safe and adequate direct care at the residential home. They directly monitor the medication administration and make sure medication errors are at a minimum. They also oversee all their medical appointments in the community.

“In the homes....so most homes, the nurse oversees the medical care, so she oversees the medication administration. She oversees the doctor’s appointment to some varying degree. Some nurses are more hands-on than others. It’s just their kind of management style, and they want to be involved in understanding how to direct the staff better in the care of these individuals.” (Jessica, DDS Service Coordinator)

Also, during the transition of care from the long-term care facility to the community, the nurse at the residential group home oversees the transfers of medication and makes sure that prescriptions are written appropriately to meet MAP requirements.

“She was the nurse for the house....so she came, and she talked to me. She would look at the medication and would say.... I’m going to have a problem with this medication. She was very pro in facilitating that aspect, and she set up a meeting with our MD for that building and sat down with him and went verbatim.... this is how I need it written; this is how I need it written.” (Nicole, Facility Social worker)

### **Provide Education and Training**

Like all the other roles of the nurse, providing education and training also occurs at the macro and micro level. At the macro level, the DDS nurse offers education to the management of the residential group homes regarding safety protocols and prevention of incidents, etc. Also, nurses at the state level run medication administration programs (MAP) for certification of the residential home staff in safe medication administration.

“I will reach out to the service agency myself, and it can go up to even having meetings. The first thing I would do is try to call them, educate them, and if I feel like it’s still not being followed up with, you know, then I would, you know, go further and try to do a meeting with them.... go and talk to House Manager....” (Kandi, DDS Nurse)

Nurses at the micro level also provided education and training to the residential home staff and directly to the patients to ensure safe care. The nurse at the residential group home was responsible for providing education and training to the staff to ensure

safe administration of medications and also training on equipment use and in competence in direct care skills.

“A 24-hour nursing is different. You'll have a head nurse that's there 24 hours a day... and they will do hands-on with the individuals, and also train the staff and oversee and supervise the staff while they're performing those complex medical services.” (Chip, DDS Service Coordinator)

Nurses also provide education to the residents on self-care management. This education was provided in the home and before discharge at the long-term care facility, even though this was perceived as unusual.

“Bea (nurse) knows what I needed, and I talked about the things that we needed to work on for training purposes for the individuals, such as administering insulin to themselves. One of them had a colostomy bag. She had to learn how to....so, they had to learn to manage that. But you know, they worked with them. They put those plans in place and every time, every month I would go she'd be like, did you see this.... the track record? So that hardly ever happens in a nursing home. I just happen to have a really, really good nurse who is invested.” (Cassandra, DDS Service Coordinator)

### **Provide Direct Care**

Finally, nurses provided hands-on care to individuals with TBI who transitioned to the home. In residential group homes that take on medically complex patients, they offer 24/7 nursing in the house, and the nurse provides all the medical care needs of the individual including tracheostomy care, management of gastrostomy tubes and administering their medications.

“It's a medical complex house. They have the tube, the trach. They have oxygen at night and an LPN. The house is supposed to have an LPN all the time for suction and everything.” (Ubda, DDS Service Coordinator)

“Nurses do the diabetes thing.... I think administering shots, or any other types of injections needs to be done by a nurse except for, I believe, Diastab. That's not an injection.” (Jessica, DDS Service Coordinator)

If the home does not have direct care nurses, visiting nurse agencies are used to provide services such as diabetes management and wound care.

“So, if it’s someone that is going to be more medically intense, we look for an agency which provides that more.... that have a higher level of nursing. Do we need VNA services for any specialized things like, you know, maybe coming in and checking coumadin or maybe coming in to do wound care? We look into that, and we’ll get a referral out for that.” (Antonia, DDS Service Coordinator)

### **Summary**

The role nurses played in this process was perceived by study participants as significant, and it varied. In transitioning individuals with TBI under the Medicaid waiver programs, the role of the nurse is seen at two levels: a macro (state) level and at a micro level within independent organizations involved with the transition process. The nurse’s role at the state level is at an expert level and comes with much responsibility through oversight and consultancy. At the micro level, the nurse role is perceived differently within settings, and sometimes is perceived as a minimal to none role by study participants. Findings from this study have revealed a disparity in perception of the nurse’s role in transitioning from the long-term care setting to the community. Further studies are needed to explore this finding.

## **CHAPTER 10**

### **DISCUSSION**

#### **Introduction**

Transitioning individuals with disabilities (including TBI) from institutional settings such as long-term care facilities to communities across the United States has been on a continual trend since the landmark ruling by the US Supreme Court *Olmstead v. L.C.* in 1999. Such transitions have been strongly supported at the federal and state level with Medicaid funding due to the asserted reduction in healthcare cost (Harrington, Ng, & Kitchener, 2011). Promoting such transitions is laudable and ongoing in states across the United States, including the Commonwealth of Massachusetts. How transitions were being managed remained unknown. To bridge the gap in knowledge, a grounded theory study to explore the process of transitioning individuals with TBI from long-term care facilities to the community was conducted. This study also aimed to define successful transitioning and the perceived role of the nurse in the transitioning process.

A theoretical model that describes the process of transitioning and transition management in the context of the phenomenon “It’s All About the Person” emerged from this study. A definition of successful transitioning as positive outcomes of the transitioning process also was found. This study also found that the perceived role of the nurse varied across the transition continuum and occurred at both a macro state level and a micro level within independent organizations throughout the transitioning process.

In this chapter, the findings on the definition of successful transitioning as a positive outcome of transitioning will be discussed and compared with current literature on TBI transition outcomes and their measures. Also, the theoretical model “It’s All About the Person” of transitioning to a community (IPMTC) will be discussed as emerging nursing theory and compared with existing transition models. Furthermore, the process of transitioning as a nursing process will also be addressed. The essence of this theory as an accurate representation of a person-centered transitioning process will be discussed. Also, to be discussed in this chapter are the crucial transition management processes, such as communication, team collaboration, relationship building, and social engagement. Included in this discussion will be the findings on the role of the nurse in this transition process in the context of the existing literature. This study found facilitators and barriers that influenced the transitioning process, which will also be discussed.

Finally, the latter part of this chapter, the contribution of this study to scientific knowledge, the study limitations, and its implication in the areas of research, practice, policy, and education will be discussed.

### **Discussion: The Definition of Successful Transitioning**

Findings from this study shows that transitioning from a long-term care facility to a residential group home setting in the community is a complicated and person-centered process. In defining the concept of successful transitioning, study participants described successful transitioning as positive outcomes of the transitioning process. Their descriptions of the outcome were both person-focused and process-focused and were both

subjective and objective. As a person-focused outcome, they viewed it as positive psychological and physical life changes noted in the individual who transitioned (see Figure 4). These life changes included individual growth, improved wellbeing, improved quality of life, individual empowerment, re-established dignity, smooth adjustment, and improved functional ability. Although many of these definitions have not been directly associated with the transitioning process, quality of life, dignity, and wellbeing are concepts that have been used as indicators of successful transitioning and have been used as outcome measures of long-term care transitions under Medicaid waiver programs (Robison et al., 2015). Measures such as global life satisfaction and some domains of quality of life, such as health and wellbeing, and treated with respect and dignity, among others, have been measured in a recent study (Robison et al., 2015). Even though the study was conducted in the state of Connecticut and was not specific to the TBI population, there is the indication that the notion of well-being, quality of life, and dignity as concepts defining successful transitioning from institutional settings to communities is broadly held. In TBI- specific studies, life satisfaction is commonly used as a proxy to measure wellbeing and happiness to show successful transitioning to the community (Burleigh, Farber, & Gillard, 1998). The finding of improved functional ability as a definition of successful transitions is also widely held by researchers in TBI transition outcome studies (Gray et al., 2018; Rosario et al., 2017; Sandhaug, Andelic, Langhammer, & Mygland, 2015). These researchers measure improved functional ability as independence, using measures such as the FIMs (Granger, Hamilton, & Keith, 1995) and other measures of functional outcomes, such as Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck et al., 1996). Others conceptualize improved



functional ability as increased participation in normal life roles such as in one's home setting, in social roles and network and productive activity and measure that with the Community Integration Questionnaire (CIQ) (Willer, Ottenbacher, & Coad, 1994). It should be noted that all of these studies were in the context of rehabilitation and looked at transitions of the individual with TBI from acute inpatient rehabilitation hospitals to community and not from the long-term care facilities to the community. Therefore, the findings of this study suggest that this measure could also be applicable in measuring successful transitioning as outcomes in long-term TBI transition studies.

As earlier shown, aside from defining transitions with a person-centered focus, participants in this study also perceived and defined successful transitioning from a process perspective. In that perspective, they described the term both subjectively and objectively. Individually, they used descriptors such as "having set goals," "having everything in place," and "having a seamless process." These definitions are difficult to measure and effort to conceptualize and measure them will be further pursued in future studies. However, objectively, they defined successful transitioning as a low number of readmissions, increased number transitioned and reduced emergency hospitalization. In current transition studies specifically in healthcare, 30 day-readmission rate and number of emergency department visits are widely used as outcome of transitions, predominantly in acute care settings, though not specific to TBI studies (Golestaneh, Bellin, Southern, & Melamed, 2017; Park et al., 2013; Wysocki et al., 2014). In those studies, a low rate or number is a desirable or positive outcome and hence, may be regarded here as successful transitioning. Given this, the findings of a low number of readmissions and reduced emergency hospitalizations in this study align with the current literature, and its

applicability in long-term care TBI transitions studies is appropriate and should be encouraged.

Community integration was not a term or concept participants in this study perceived as defining a successful transitioning to the community, although it is widely used as a measure of positive transitioning outcome in studies specific to the TBI population (Rosario et al., 2017). In fact, one study did identify that higher levels of community integration and quality of life were associated with transition success (Nalder, Fleming, Foster, et al., 2012). Their omission of this term by study participants as defining successful transitioning may be due to the lack of knowledge or understanding about this concept. I assert this because in their extensive interviews they described many instances where efforts were made to ensure the individual's community integration. For example, they fostered individual's participation in the community through work and socialization and encouraged their functional independence. These elements are widely defined as indicators of community integration by Willer et al. (1993) as measured on the CIQ. However, when asked directly to define successful transition, community integration was not a term they used.

Overall, how study participants perceived and defined successful transitioning as person-focused or process- focused was not surprising because transitioning, as studied here, was found to be all about the person and was a process over time. This held belief of the participants may have shaped their perceptions of what successful transitioning is. The definitions such as personal growth, empowerment, adjustment, and the subjective descriptions of process outcomes may be difficult to measure and needs to be conceptualized and operationalized in future studies.

## **Discussion: “It’s all about the person” Model of Transitioning to Community**

### **(IPMTC) - An Emerging Nursing Theory**

The primary aim of this study was to develop theory. Using a constructivist grounded theory approach, the IPMTC was developed as a theoretical model. Even though most of the study participants were professionals from other disciplines outside of nursing, the IPMTC fits the primarily held notion of what a nursing theory ought to be. According to Meleis, a nursing theory is one that conceptualizes some aspect of nursing reality, describes a phenomenon, explains relationships between the phenomenon, and either predicts consequences or prescribes nursing care (Meleis, 2012). The IPMTC does that, as will be further discussed.

The IPMTC conceptualizes and describes the phenomenon of transitioning to the community as being all about the person. Transitioning from a long-term care facility to the community was found in this study as a person-centered but interdisciplinary process, with nurse involvement and supports. The IPMTC identifies well-being, quality of life, choice, personal needs, human rights, communication, planning, team collaborations, relationship building, coordination, and social engagement as some of its key concepts (see Figure 5). It also explains the relationship among the identified concepts and proposes a set of broad assertions. Transitioning of an individual with TBI from a long-term care facility to community under a Medicaid waiver program will have positive transition outcomes if:

- 1) It is person-centered such that the individual's personal needs, preferences, goals, safety, human rights, emotional sentiments, wellbeing and quality of life are respected throughout the transitioning process.
- 2) A supportive environment is maintained throughout the process, such that there is availability and easy access to community resources as well as formal and informal supports.
- 3) The health of the individual transitioning is maintained in a stable equilibrium between wellness and illness.
- 4) There are efficient transition management processes in place such as checking in, communication, planning, team collaboration, relationship building, and coordination.
- 5) There are facilitating individual, process and organizational factors in place (see Figure 28)

Finally, the IPMTC also has prescribed consequences through its assertion that transition outcomes will be suboptimal if there are barriers to the process. Such barriers may include complex medical conditions, dysfunctional communication, and other systems and organizational barriers (see Figure 29). However, these assertions have yet to be tested, and lay a foundation for future studies. Also, this model is prescriptive and gives an in-depth description of how to manage a transitioning process of an individual with TBI from a long-term care facility to the community under the Medicaid waiver program. The transitioning process as managed is synonymous with the nursing process, which will be further discussed later in this chapter.

The IPMTC also fits the definition of other theorists, including the definition of Chin and Kramer. They define a nursing theory as “a set of concepts definitions and propositions that projects a systematic view of a phenomenon by designating interrelationships among concepts to describe explaining, predicting, and controlling phenomenon” (Chinn & Jacobs, 1978). The IPMTC projects a systematic process of transitioning across a continuum of phases from the pre-transition stage through a transition phase to a post-transition phase. The IPMTC also describes interrelationships among concepts and shows factors that influences the phenomenon of transitioning, however it is yet to be tested. The IPMTC is congruent with Fawcett’s definition of a nursing theory, which asserts that a theory is relatively specific and has a concrete set of concepts and propositions that accounts for a phenomenon of interest to the nursing discipline (Fawcett, 1985). The IPMTC is further strengthened as a nursing theory because it addresses the four constructs (person, health, environment, nurse) included in the metaparadigm of nursing (Fawcett, 1984).

The IPMTC defines a person as a bio-psychosocial being with choices, human rights, personal goals, needs, and emotional sentiments who maintains a stable health and builds relationships through social interactions, and social engagement in a supported environment and whose safety, dignity, well-being, and quality of life is enhanced during his/her transition to the community (See Chapter 5). Health in the IPMTC is referenced in the model as maintaining stable health. Maintaining stable health is achieving and keeping a balance between wellness and illness in persons with chronic diseases, including TBI. Furthermore, in the IPMTC, the nurse is part of a collaborative team and supports the person during transitioning to the community and ensures his/her safety and

maintenance of stable health. Finally, the environment in the IPMTC is a supported environment and defined as an environment where there is availability and easy access to community resources and either formal or informal supports or both. It is appropriate to indicate that the IPMTC is most certainly an emerging nursing theory.

Nursing theories are distinguished by their level of abstraction. Meleis identifies three types of theories in nursing, based on their levels of abstraction, and they include grand theories, middle range theories, and situation-specific theories (Meleis, 2012). Grand theory is grand in that it has a broad scope and shows relationships between many abstract concepts. Grand theories are not easily subjected to empirical testing (Meleis, 2012). Middle range theories, on the one hand, have a limited scope, are less abstract, and they address specific phenomenon or concepts and reflect practice (Meleis, 2012). Unlike grand theories, middle range theories are easily tested empirically because their concepts are more specific and readily operationalized. Situation-specific theories are limited, as they are focused on a particular phenomenon of nursing and reflect clinical practice. They are also limited to specific populations or to a particular field of practice. Based on these definitions, I suggest that the IPMTC is an emerging middle-range theory. Although it is grand in size, it addresses a phenomenon and reflects a variety of nursing care situations. Many of its concepts, such as wellbeing and quality of life, have been operationalized for empiric testing. However, others are yet to be conceptualized and operationalized. An argument could also be made that the IPMTC is a situation-specific theory, since it is specific to transitions from long-term care facilities to the community under the Medicaid waiver program and specific to TBI populations. However, the scope of this theory is not as limited as it appears, because it is a person-centered process. The professional

caregivers and residential service providers interviewed in this study repeatedly indicated that their processes were not specific to individuals with TBI, but to any person who they had on their caseload. It should also be noted here that the ABI Medicaid waiver program is open to all persons living in long-term care facilities for at least 90 days with an acquired brain injury after the age 22. This includes individuals with a TBI diagnosis. The MFP Medicaid waivers, on the other hand, is open to all persons 18 years and older living in a long-term care facility for at least 90 days with chronic illness or disability, including TBI, spinal cord injuries, multiple sclerosis, Gillian Barre syndrome, diabetes, mental illness, etc. The professional caregivers who participated in this study have a mixed caseload, and they manage transitions of persons from both waiver programs and use the same process. Therefore, by default, this theory could potentially apply to these populations as well.

The IPMTC compares well with other existing theories and models involving transitions. Like the transition theory (Meleis et al., 2000); Transitions Intervention (Gardner et al., 2014) and Transitional Care Model (Naylor et al., 2009), and Care Transitions Intervention (Coleman, Parry, Chalmers, & Min, 2006).

The IPMTC aligns well with transition theory in the assertion that transitions are complex and multidimensional. They are characterized by a flow of movement over time and cause change in fundamental life patterns (Meleis et al., 2000). The IPMTC as depicted in Figure 5 is complex and multidimensional, as it can be viewed both at a macro and micro level and it involves a sophisticated collaborative team. The concepts shown in this model are also complex. The IPMTC characterizes a flow of movement along three phases from pre-transition through the transition to post-transition over time.

Like Meleis's transition theory, transitions based on the IPMTC also results in changes in the fundamental life patterns of the individual involved. In this study, there were positive life changes noted in the individual who transitioned to the community under the waiver program. Some of the positive changes reported included positive individual growth, improved functional ability, improved well-being and quality of life, among others, as shown in Figure 4.

Though congruent to Meleis's transition theory in many of its assertions, the IPMTC is also significantly different. In transitions theory, transitions are broadly defined to include developmental transitions, situational transitions, health /illness transitions, and organizational transitions. The IPMTC defines transitions narrowly as the movement from one healthcare setting to another. In reference to Meleis's transition theory, the definition of transition as espoused by the IPMTC fits a situational transition. Furthermore, the IPMTC expands the transition theory in the areas of transition conditions, as suggested by Meleis (Meleis et al., 2000). Meleis identified personal factors including meaning, cultural beliefs and attitudes, socioeconomic status, preparation, and knowledge as the facilitating and inhibiting factors of transitions. However, the IPMTC identifies other enablers and barriers, described as individual factors, process factors, and systems and organizational factors (Figures 28 & 29). This is an obvious extension of the personal factors identified in Meleis's transition theory.

Finally, there are distinct differences between nurse roles in the two theoretical models. In transition theory, nurses and other health professionals are regarded by Meleis as integral to this process (Meleis, 2010). Meleis pointed out that in our daily practice of nursing, nurses encounter role changes, such as the transition from wellness to illness,



birth to death, and nurses are therefore well positioned to assess and address the patient's psychosocial needs and provide necessary interventions. (Meleis et al., 2000).

In the IPMTC, the nurse is not as integral to the process, but a part of a collaborative team. The nurse's role of assessment to address the patient's psychosocial needs and provide necessary interventions was upheld in this theory. However, in this model, the nurse assumed different roles along the transition continuum on both a macro and micro level. Nurses in this process had roles in assessment, education and training, direct care, and clinical oversight. Their prominent role in nursing was mainly to provide clinical supervision and expertise, and was more a supporting role.

The IPMTC also compares well with the other transition models and incorporates concepts of transition management processes which are focused in both the Transitional Care Model (TCM) and the Care Transition Intervention Model (CTI). Both models are based on interventions to prevent 30-day readmissions or rehospitalizations upon discharge from either an acute care setting or a skilled nursing facility. The TCM (Naylor et al., 2009) however, is focused on high risk older adults and involves a one to three-month period of interventions to prevent re-hospitalization. Interventions include identifying pertinent risks, employing the role of an advanced practice nurse, and providing supports through APRN nurse visits, communication by phone, and follow up. This model also relies on patient engagement, goal setting, and communication with patient, family, and healthcare team (Cesta, 2017; Naylor et al., 2009).

On the other hand, the CTI by Coleman is a four-week program to foster patient engagement and promote safe transitions from the hospital and skilled nursing facilities to home. The CTI also identifies four pillars for safe transitions, including medication

management, maintenance of health records, primary care provider follow-ups, and alertness to red flags. Like the TCM, the CTI has built-in supports through a transition coach, home visits, and communication by phone after discharge with the focus on follow up care with primary care providers (Cesta, 2017; Coleman et al., 2006; Parry, Coleman, Smith, Frank, & Kramer, 2003).

The IPMTC is not specifically an intervention model, but likely the first process model to be developed on transitioning that incorporates the process of transition management as well. Like the TCM and the CTI, it assesses and identifies risk throughout the process, but more significantly, at the pre-transition phase through an elaborate process of checking in. The IPMTC does not only assess for risk, but initiates an extensive planning process to formulate strategies that will work based on the individual's needs, goals, preferences, and risks. Unlike both the TCM and the CTI, transitioning is not relegated to one individual, such as an advanced practice nurse (Naylor et al., 2009) or a transition coach (Coleman et al., 2006). It is initiated and implemented as a collaborative team where all parties have shared tasks, shared goals, and shared decision making, a phenomenon that has been proven to work well when dealing with complex work such as in transition management (Gittell, 2012). The IPMTC, like the CTI, is person-centered. However, person-centeredness in the IPMTC goes beyond the use of a dynamic patient-centered record (Parry et al., 2003). With the IPMTC, the person is regarded as the expert in his/her transitioning to the community and all his rights, including the right to fail, are respected. Unlike the CTI, the IPMTC is not focused entirely on safety, but on success as defined by the person and their family. Like both the TCM and the CTI, the IPMTC emphasizes visits, frequent communication, and

follow up in the community. However, follow up and case management by service coordinators is ongoing in the IPMTC and occurs every three months if the individual remains in the community. In addition, the IPMTC emphasizes the significance of relationship building throughout the process of transitioning from a long-term care facility to the community. In addition, the IPMTC works in a supported environment where there is availability and easy access to community resources and formal and informal supports.

The IPMTC is uniquely different, not only because it is the only model that emphasizes true person-centeredness, but it is the single transition model that addresses the psychological processes or emotional sentiments that the person experiences as he/she is being transitioned to the community. The IPMTC also focuses on social participation and engagement and focuses on the processes of fostering normal aspects of life for the individual with a disability and other chronic illnesses in the community. The IPMTC is the only model that proposes transitions as ongoing at the post-transition phase and extends beyond 72 hours and includes three phone calls, as offered by CTI (Coleman et al., 2006) and three months by the TCM (Naylor et al., 2009). Finally, the IPMTC is a transition model with potential for applicability at both a macro state level and at a micro level within independent organizations.

### **Discussion: The IPMTC as a Nursing Process**

“Nursing process is an orderly, systematic manner of determining the client’s health status, specifying the problems, initiating and implementing plans to solve them, and evaluating the extent to which the plan was effective” (Johny, Moly, Sreedevi, &

Nair, 2017). This process occurs in five identifiable steps: assessing, diagnosing, planning, and evaluation (Baraki et al., 2017). The nursing process was identified as a four-step process, and in 1974, the nursing diagnosis was added and adopted by the American Nursing Association as a distinct and separate step in the nursing process (Gebbie & Lavin, 1974). In the United Kingdom, the nursing process still comprises of four main stages, assessment, planning, implementation and evaluation (Younas, 2017). IPMTC depicts the four of the five steps of the nursing process; and aligns more with the current UK version of a nursing process, as will be discussed in detail. Assessment involves the collection of data related to the individual's health status. Planning is a decision-making phase, where the nurse arrives at some conclusion regarding the nursing measures to use in order to adequately meet the individual's needs (Humphris, 1979). At this stage of the process, the nursing care plan is developed (Ballantyne, 2016; McGilloway, 1980). In a teaching context, this is also a stage when teaching objectives and outcomes are set in a teaching plan (Younas, 2017). The implementation stage of the nursing process is when the nursing care plan is implemented, and the stage is set for further observation as to the accuracy of the plan (Humphris, 1979). The implementation phase of the nursing process in a teaching context is described as the actual teaching of content and strategies (Younas, 2017). The final stage of evaluation is to determine the effectiveness of the care given to the patient (Humphris, 1979).

The application of the nursing process in nursing practice has been associated with positive outcomes such as improving the quality of nursing care (Johny et al., 2017; Pokorski, Moraes, Chiarelli, Costanzi, & Rabelo, 2009). The nursing process has also

been attributed to improvement in attitudes and skills required for clinical judgment (Kim & Shin, 2016).

### **The IPMTC as an Assessment Process**

The checking-in process of the IPMTC, as described in the pre-transition phase of transitioning in Chapter 7 and depicted in Figure 18, is an assessment process. It is a stage where data is collected or gathered. It is a stage that necessitates careful and accurate observation, and as described by Humphris (1979), it is the first step of a scientific method (Humphris, 1979). During the checking-in process, the professional caregivers engaged in information seeking, where they interviewed the individual transitioning and staff at the long-term care facility about his /her care needs, goals, preferences, and risks. They also gathered information through direct personal assessment or by reviewing medical records. If the individual had medical complexities, expert advice was sought from the nurse at DDS to further assess the individual for risks that may preclude his/her safe and successful discharge to the community. The assessment was ongoing on average at three-month intervals. The frequency of assessments also varied and could occur monthly based on the person's risks or needs. Assessments could last about a year or more, since it took that long to transition from the long-term care facility to the community under the waiver program. The assessment was prominent at pre-transition phase but also occurred at the move in or transition phase, when professional caregivers assessed the individual to determine what type of services they needed to put in place during the initial ISP meetings. Such assessments continued through to the post-transition phase where the individual was assessed every three months

for any change in status and yearly at redetermination for program eligibility. Assessment in IPMTC is comprehensive and is congruent to the nursing process (Younas, 2017).

### **The IPMTC as a Planning Process**

Like the nursing process, the IPMTC also describes a systematic planning process (see Figure 18). At this stage of the nursing process, a set of decisions are arrived at, that is best to meet the individual's needs and incorporated into a nursing care plan (Humphris, 1979). During planning in the IPMTC, the individual needs, goals, preferences, and risks identified at checking-in are incorporated into the decision -making process. Also, new needs, goals, preferences, and risks are also determined at this first step of the planning process. These occurrences are synonymous with how planning occurs in a nursing process (Humphris, 1979; Younas, 2017). Once these are identified, there is a formulation of strategies to develop a preliminary individual service plan (ISP) synonymous to a plan of care in the nursing process (Ballantyne, 2016; McGilloway, 1980). Formulation of strategies in the transition process is equivalent to the critical thinking elements of the nursing process. It is primarily coming up with the best executable plan that will foster a smooth or seamless transition process. In this process, the collaborative team engaged in brainstorming and relied heavily on expert opinions among the collaborative team, including the individual with TBI.

### **The IPMTC as an Implementation Process**

The implementation step in the nursing process is about applying the plan of care to patient care or nursing practice (Humphris, 1979; Younas, 2017). In the IPMTC,

implementation occurs broadly at a macro level and specifically at a micro level.

Implementation in the IPMTC was also about putting the initiated transition plan into action. Once a plan is formulated or developed and goals are set, the planning process moves on at the pre-transition phase to an implementation phase (see Figure 18). During the implementation phase, tasks are assigned to team members with set expectations and timelines. Implementation at a micro level could involve making referrals to a primary care physician and setting an appointment for the individual to be seen in the community upon discharge. It could also be getting a physician to write a script appropriate for MAP medication administration in the community or making a referral for transportation and durable medical equipment. The goal at the end of the implementation phase is to ensure that set goals are met and the formulated plan is executed as best as possible. Looking at IPMTC on a much higher (macro) level, the implementation step will be at the move in phase/transition phase of the process. This move in phase is where there is the actual movement of the individual with TBI from the long-term care facility. At the macro level, the plan to transition the individual with TBI out of the nursing facility is implemented at this phase of the process. Again, IPMTC proves to be congruent with the nursing process as having been described (Humphris, 1979; McGilloway, 1980; Younas, 2017).

### **The IPMTC as an Evaluation Process**

The final step of the nursing process is the evaluation stage. At this stage of the process, the patient's progress in terms of the established goals and outcome criteria are evaluated (McGilloway, 1980; Younas, 2017). Based on the IPMTC, an evaluation process synonymous to the nursing process occurred as a final step in the planning

process. The evaluation stage in the transitioning process was to reassess the initial formulated plan and determine if it was entirely followed. Evaluation occurred during subsequent transition meetings to ensure that any obstacles to the process were brought back to the team and new strategies formulated if necessary to address them before the move to the community. Evaluation in the IPMTC is not a single occurring event, and it can be recurrent with multiple transition meetings until the set plan is thought to be fully or close to fully implemented. Professional caregivers interviewed were adamant that transitions were held off until “everything was in place.” Also, in considering the entire transition process, evaluation occurs at the post-transition phase or living in the community phase, where annual redeterminations are done to reassess the individual service plans. A description of the IPMTC, as outlined through processes of assessment, planning, implementation, and evaluation, indicates it is a nursing process, even though, ironically, the nurse is not central to the process.

### **Discussion: The IPMTC as a Person- Centered Process**

In the early 1940's, an American psychologist by the name of Carl Rogers created the notion of person-centeredness. The principles of his theory were that each person possesses essential qualities, can draw strength from available resources, and can find ways to remedy difficulties (Rogers, 1961). In this context, the person is central to their decision making. They are considered experts in their care needs and can find solutions to their problems within their limited resources. Therefore, using a person-centered approach requires a focus on the person's needs and respect for their values, preferences, and autonomy (Morgan & Yoder, 2012). A successful person-centered



approach supports informed decision making, fosters creative problem-solving strategies by incorporating strategies for engaging supports, and negotiating service agreements geared to meet the unique needs of the individual and their family caregivers. (Sundar, Fox, & Phillips, 2014).

In light of this, the IPMTC uses a person-centered approach in transitioning an individual from a long-term care facility to a residential group home in the community. The IPMTC focuses on the person's needs, choices/preferences, and goals. It also respects the person's values and his/her human rights. The person in this theoretical model is regarded as an expert in his/her own right and is part of the collaborative team. In this process, there is shared decision making. If the person is deemed capable, he/she is fully involved in the decision-making process and is present at all transition meetings. Shared decision making has been found as an antecedent of the concept of person-centered care (Morgan & Yoder, 2012) and regarded as a hallmark of person-centeredness (Atkinson Smith, 2016). In situations where there are significant cognitive deficits, the individuals' autonomy is preserved, and a legal guardian makes decisions on behalf of the person. The person is the driver of his or her transition to the community. Professional caregivers make an effort to get to know the person at the very beginning of the process. Knowing the person in this study involved knowing their needs, preferences, and their set goals. In the IPMTC, transition moves forward only when knowledge of person has been established at "checking-in." The entire transition management process from pre-transition through the transition to post-transition, is centered around the person and his/her needs (see Figure 5). The IPMTC gives the person lots of choices and preserves their right to social participation in the community as well. In Chapter 5 the

core phenomenon of “it’s all about the person,” as presented, gives a deeper understanding of the true meaning of a person-centered process. In fact, based on the strong interpretation and belief study participants attributed to this phenomenon, there were a few instances where there were resulting conflicts between one’s human rights and another’s safety. Such conflicts are common in healthcare and pose an ethical dilemma in pursuing person-centeredness (Fraser, 2004; Quigley, 2016). In a true person-centered transition process, as presented in the IPMTC, the premise raised by study participants that a person “has the right to fail” is supported. Therefore, the onus falls on the collaborative team of professionals, including nurses, to provide expert information and support so that the individual and guardian can make an informed decision based on their needs, goals, and preferences. This principle of practice aligns also with a core principle in the Code of Ethics for Nurses (Quigley, 2016).

### **Discussion: Transition Management Processes**

The transition process is complex and has a lot of moving parts, as shown in Figure 5. It requires complex coordination among a team of professionals, community service providers, the individual with TBI, and family caregivers. This complexity requires effective management of the process. There is a held notion that effective management of care transitions is critical in improving patient outcomes and reducing cost (Huber, Shortell, & Rodriguez, 2017). Therefore, efforts at improving transition management in healthcare are ongoing (Yoder, 2017) with new training programs for nurses in care coordination and transition management (Alban, 2015; Haas, Ann Swan, & Haynes, 2013). Also, there is an ongoing trend towards the development of transition

intervention models for effective discharges (Altfeld et al., 2013; Coleman et al., 2006; Naylor et al., 2009). Currently, no model places transition management within the context of an overall transitioning process, a gap which the IPMTC has bridged. From this study, key transition management processes have been identified as key to successful transitioning outcomes, and these include communication, coordination, team collaboration, relationship building, and social engagement.

Communication existed throughout the transition process among the collaborative team. This finding aligns with currently prescribed interventions of transition management as suggested in existing models (Coleman et al., 2006; Naylor et al., 2009; Stefanacci & Haimowitz, 2014). Effective communication, as reported in this study, helped in coordinating both the larger transition process and coordination of services for continuity of care. Communication also helped strengthen relationships individually among professionals and assisted in building a cohesive team. Interdisciplinary collaboration is known to be useful when there is effective communication among its members (Rose, 2011). This study also found that communication, coordination, and team collaborations were mostly described together and occurred together during this transitioning process (see Figure 16); indicating a probable correlation, which will be further explored.

Another key finding in this study was the fact that relationship building is a key transition management process. In this study, successful transitioning was fostered through social and professional interactions in relationship building. For example, participants expressed how relationships with community service providers helped in ensuring a smooth process. This phenomenon of relationship building during

coordination of a complex task such as transitions is similarly reported by Gittel in the relational coordination theory (Gittel, 2012). In her theory, she espouses that social processes and human interactions enhance team collaboration through shared goals, shared decision making, and mutual respect (Gittel, Godfrey, & Thistlethwaite, 2013). Though this phenomenon may be occurring in transitions across healthcare settings, it is missing or at best not an emphasis in existing transition intervention models (Altfeld et al., 2013; Coleman et al., 2006; Naylor et al., 2009). The IPMTC has bridged this gap in describing this phenomenon in the context of transitioning from a long-term care setting to the community, as depicted in Figure 17.

Furthermore, social engagement is regarded in this study as a transition management process. Professional service coordinators and community service providers ensured that the individual with TBI participated socially in the community upon their discharge to the community. Individuals with TBI have reportedly experienced high levels of social isolation (Engström & Söderberg, 2011; Mukherjee, Reis, & Heller, 2003; Turner et al., 2007; Winkler et al., 2011) and loneliness (Sollid Manskow et al., 2015) as they transition to the community. This isolation has been associated with increased emotional distress (Kent, Wright-St Clair, & Kersten, 2014) and poor community integration (Doig, Fleming, & Tooth, 2001). The IPMTC helps to address this issue of social isolation by fostering social engagement and providing a supported environment through the availability of accessible community resources, such as peer supports, day program services, rehabilitation and residential habilitation, and formal supports through professional interactions such as case management, and informal supports through peers and family caregivers. Current evidence suggests that having higher levels of supports

significantly helped individuals with brain injuries and their families in areas such as development of new friendships and contacts (Bellon, Sando, Crocker, Farnden, & Duras, 2017).

Furthermore, findings from this study also reported that participants did not particularly like attending day programs and preferred to stay in the residential homes. However, they said they were happy with their life. This may suggest that using participation in the community to measure one's re-integration into the community, as is currently being measured by the community integration questionnaire (Willer et al., 1994), may not reflect accurately the subjective experiences of the individual with TBI who transitioned from a long-term care facility to a residential home in the community. The findings from this study also suggested that though the individual with TBI might not have participated in day programs, they did other enriching activities within the home. They also interacted closely with staff, peers and other family members within the group homes. Existing studies affirm that having positive social interactions results in happiness (Bernstein, Zawadzki, Juth, Benfield, & Smyth, 2018; O'Connell, Gallagher, & O'Shea, 2016; Oishi et al., 2008).

### **Discussion: Factors Influencing the Transition Process**

There were many factors found in this study that either directly or indirectly influences the transition process and outcomes. These factors were either positive (facilitators) or negative (barriers). The factors identified were individual factors, process factors, and system and organizational factors, as shown in Figures 28 and 29. Among the individual factors, positive attitude to therapy and family involvement were found to

influence the process positively. This was not surprising, as earlier studies report that individuals with TBI and their families found rehabilitation services as their most salient support needs (Nalder, Fleming, Cornwell, Foster, Ownsworth, et al., 2012; Nalder et al., 2016; Turner et al., 2007; Turner et al., 2011; Turner et al., 2008). Hence, they were more likely to have a positive attitude towards therapy. Also, the findings that family involvement is favorable to the transition process is widely reported (Fields et al., 2011; Leedahl et al., 2015; Meador et al., 2011; Noyes et al., 2014; Robison et al., 2012). Interestingly, participants felt that family over involvement posed a barrier to their process, since family did not always understand their process and had unrealistic expectations for their loved ones.

Also, of significance was the finding that residential group home staff had a perception that long-term institutionalization had a negative effect on individual's motivation to self-care management and their transitioning outcome. This effect on transition has not yet been directly studied. However, a study that looked at the effect of institutionalization on persons with schizophrenia indicated that, if any, the impact of their institutionalization is relatively small in areas of the mental state and cognitive, behavioral, and neurological functioning (Johnstone, Owens, Gold, Crow, & MacMillan, 1981). Furthermore, this study found that professional caregivers having negative perceptions of the individual with TBI was a barrier to the process. Participants described that individuals with TBI with prior forensic history or drug use were perceived as high risk and unsafe for the transition to the residential home, making their placement difficult. Evidence exists that such negative perceptions of illicit drug users among professional health care providers are common. Unfortunately, such attitudes cause

prejudice and block the professional from carrying out effective and humane nursing care to this population (McLaughlin & Long, 1996).

Regarding the process factors influencing transitions, this study found that professionals with an in-depth knowledge of the transition process affected the process positively, as they understood program requirements and were able to plan smooth transitioning adequately. Likewise, lack of understanding or knowledge about the program and transition process was a barrier to positive outcomes. This finding aligns with findings in a recent study that looked at transitional care in skilled nursing facilities. Research reported that a lack of staff knowledge about the transitional care processes might have contributed to poor outcomes for the patient (Toles et al., 2016). In addition, effective transition implementation strategies such as effective communication, effective planning strategies, and effective team collaboration influenced the process positively. This study found that communication occurred throughout the process and the mode of communication used varied. However, communication was sometimes dysfunctional, causing frustration among team members and affecting relationships within the team. Dysfunctional communication resulted in the development of mistrust among individuals within the collaborative team. This sometimes led to unnecessary delays in the transition process. Dysfunctional communication during transitioning processes is common and has been reported elsewhere (Abrahamson et al., 2016; Piccenna et al., 2016; Toles et al., 2016). Effective communication has been found to be essential to practice and can result in improved interpersonal relationships at the workplace (Grover, 2005). Using communication techniques such as open-ended questions, listening, empathy, and assertiveness is basic to effective communication (Grover, 2005). Furthermore, this study

found that having efficient team collaboration helped to enhance the process. Six elements have been reported as essential in having an effective team: shared an identity, clear roles/tasks/goals, interdependence of members, integration of work, and shared responsibility and team tasks (Reeves et al., 2010). In this study, a number of these elements were found, including other elements not indicated by Reeves et al. (2010). These included having a team, shared decision making, problem-solving, shared tasks, working with experts, and relationship building.

Despite the presence of these elements of team collaboration, participants in this study expressed frustration working with the collaborative team. For example, they felt that the long-term care facility team were themselves barriers to the process, because they often did not understand their roles, and did not deliver on their tasks. Though some team members verbalized that they were “all working towards a common goal,” I felt this was more an assumption on their part since many of the individuals did not share in their common goal or did not verbalize that in our interview sessions. A “real team” is described as one where members share common goals and share some accountability. “High-performance teams” are teams whose members all hold a clear understanding of their roles, share common team goals, and encourage members’ personal development (Reeves, Xyrichis, & Zwarenstein, 2018). Therefore, findings suggest that there is room for improvement, and efforts to improve team collaboration in this process is needed to minimize member frustrations and optimize overall process outcomes.

Finally, system and organizational factors were also noted to influence this process. Having organizational commitment, including staff commitment to the process, have been found to influence the process positively. Dedicated staff, who were



committed to the process, were more likely to follow through with treatment plans and work effectively with service providers and professionals in the community to help foster positive outcomes. On the other hand, organizations and their staff who were not committed to the program were likely to be uncooperative with the process, have poor management practices, and give inadequate training to their staff. Staff within these organizations were also likely not to follow through with tasks due to poor management they receive. Staff attitude within such organizations may also be negative. Professional caregivers reported negative attitudes from long-term care facility staff and felt they created an unfriendly work environment, which affected team collaboration and the efficiency of the transition process.

Having latitude with the waiver program positively influenced the process. The waiver program has a lot of inbuilt supports, and it is funded both at a state and federal level. Therefore, it gives the professional caregivers latitude to put in place the right services and also obtain the most effective durable medical equipment needed to meet the needs of the individual, thereby enhancing program outcomes. Unfortunately, such latitude is not always available in other transition programs, which may give transitions under the Medicaid waivers undue financial advantage over regular discharge processes. However, the positive outcomes reported in this study also makes the argument that when money is invested in transitioning processes, outcomes are likely to be positive. The MFP Medicaid waiver program in Massachusetts was developed based on the Affordable Care Act provisions to expand Medicaid services to low-income individuals. The positive outcomes reported by study participants is proof that when healthcare is affordable and

accessible to low-income individuals, they experience personal growth and have improved outcomes in their wellbeing and quality of life.

Despite such positive outcomes, the waiver program has strict regulations in place to control cost. It is a selective process, and many do not qualify for waiver services due to its strict eligibility criteria. Also, services under the waiver program are not always available and easily accessible, especially in the rural areas due to lack of trained professionals. Some community service providers indicated that low reimbursement rates by the state made it less feasible for them to provide services in the remote and rural locations.

Participants also reported the lack of housing under the waiver program due to market factors and regulations by cities and towns. This problem is common among many Medicaid waivers across the United States, and critics of these programs have gone as far as to suggest that states are not ready to run such programs (Fields et al., 2011).

### **Discussion: The Role of the Nurse**

Findings reported in this study showed that the role of the nurse in the transition process varied and included assessment, education and training, providing clinical oversight, and direct patient care (see Figure 30). The nurse role also occurred both at a macro state level and a micro organizational level. However, the perceptions of the nurses' role in transitioning under the Medicaid waiver program differed and ranged from no nurse role or minimal nurse role to expert nurse role. Perceptions of the nurse's role changed positively along the continuum and across the settings. The nurse at the long-term care facility end of the process was perceived as having no or minimal role in the

process. At the community level, the nurse was regarded as an expert who offered her expertise by providing clinical oversight and through consultancy. Such discrepancies in perceptions, especially at the long-term care facility end of the process, are of concern and are disheartening. Current efforts by nursing organizations such as the American Academy of Ambulatory Care Nursing (AAACN), the Association of Rehabilitation Nursing (ARN), and Academy of Medical-Surgical Nurses AMSN to promote a larger role for nursing in transitioning management (Camicia et al., 2014; Haas et al., 2013; Yoder, 2017), are steps in the right direction. These differences in perceived nurse role may be due to the relegation of the nurse's role in transition and discharges to the social workers in long-term care facilities, where social workers take a more visible and lead role in coordinating discharges, especially with the waivers. Also, the marked differences in educational background between the licensed practice nurse (LPN) and bachelors and/or masters prepared social workers (MSW) may also play a role. The higher educational background of the social workers makes them confident and competent in managing transitions in the long-term care settings. Hence their dismissal of the importance of the nurses' role in transitions. The inadequate preparation of many nurses who enter long-term care practice brings to question their competency and contributes to the negative perception and low regard of the nurse's role in that setting (Kaldy, 2007). Nursing homes may have to increase the skill mix at the facilities to include more registered nurses (Seblega et al., 2010) to improve such situations. Also, nurses in long-term care should be required to develop their competency (Eliopoulos, 2012). Furthermore, the low participation of the nurse in transition management could be due to the high patient to nurse ratio at long-term care facilities and more substantial

caseload (Trossman, 2001). Therefore, taking on transition management may be perceived as an added task, and hence their reluctance to take on a more visible role. These problems may be further exacerbated with the high turnover of nurses in such facilities (Castle, 2006; Trossman, 2001), making their tasks harder and preventing them from taking on a more visible role in transition management. In the community, the nurse was highly regarded due to their professionalism, skill, and higher educational status compared to the residential home staff.

### **Reflections on Current Findings**

“Care transitions” has been a buzz word in healthcare in recent times and a focus on nursing studies to improve 30-day readmissions and re-hospitalizations. Scholars have come up with intervention models as frameworks for safe discharges in efforts to reduce 30-day readmissions among patients. Models developed include the Care Transition Intervention (CTI) (Parry et al., 2003); the Transition Care Model (TCM) (Naylor et al., 2009); Re-Engineered Discharge (Project Red) (Altfeld et al., 2013), and Interventions to Reduce Acute Care Transfers (INTERACT) (Ouslander et al., 2011). These current models are focused on transition management processes such as coordination, medication reconciliation, communication, follow up, and patient engagement, among others. However, they fail to place transition management in a broader context of the overall transition process as the individual moves from one healthcare setting to another, despite the general assertions made by Meleis in her transition theory. In her theory, she explained that transitions are complex and multidimensional (Meleis et al., 2000). An individual transitioning may experience multiple transitions at the same time, which

could be developmental, situational, health/illness, and organizational. Therefore, this suggests is that an individual going to the community may be going through other transitions which may impact his/her discharge process as well and cannot be ignored. She went further to describe personal factors including culture as facilitators and inhibitors to the transition process. However, current transition intervention models do not even consider these factors. Using a true person-centered approach as suggested by the IPMTC helps to bridge this gap, as it identifies the other transitions which may be occurring in the life of the individual so effective transition plans will be developed to mitigate the added risks, if any, such changes may bring to the discharge process.

Though many studies using existing intervention models do report improvement in readmission rates, current rates remain high (Birmingham & Oglesby, 2018; Moye, Pui Shan, & Miller Thurston, 2018). The Centers for Medicare and Medicaid Services (CMS) currently reports hospital readmission data publicly, and since October 2015, there has been a reduction in payments to hospitals due to higher readmission rates (Moye et al., 2018). CMS data indicate that approximately 20% of Medicare beneficiaries are readmitted within 30 days of discharge (Moye et al., 2018). Therefore, continual efforts to improve outcomes is needed. The IPMTC presents a number of transition management processes that could be useful across other settings and could potentially help address some of these problems. Future studies using the IPMTC in acute care setting is needed to validate this hypothesis.

As I further reflected on the findings of this study, a revisit of the literature was done, consistent with grounded theory, to look more broadly at care transitions outside of the long-term care setting in order to understand the transition management processes.

This review of literature further indicated that care transition studies are currently focused on high-risk patients with chronic illnesses, such as Chronic Obstructive Pulmonary Disease (COPD) (Agee, 2017; Raley & Baker, 2016) and Congestive Heart Failure (CHF) (Long, 2017), and not TBI. These studies were primarily focused on acute care settings, with few studies looking at long-term care transitions (Naylor et al., 2009; Toles et al., 2016). This finding remained consistent with the prior review in Chapter 2.

A look back on the prior review of the literature in Chapter 2 showed a disjoint in the transition literature across key disciplines focused on studying this phenomenon. As a recap, scholars from rehabilitation science also focused on transition studies. Unlike their nurse counterparts, they looked at TBI transitions, though they also focused on acute care settings but presented a different perspective. These studies looked at transitions in a broader context and described the experiences of the individual with TBI and their caregivers during their discharge to the community (Turner et al., 2007; Turner et al., 2011; Turner et al., 2010). These studies mostly used a qualitative approach (Nalder, Fleming, Cornwell, & Foster, 2012; Nalder et al., 2013). Their findings suggested that the individual with TBI and their caregivers experience significant life changes resulting in increased emotional distress as they learned to readjust to life in the community (Piccenna et al., 2016; Turner et al., 2007; Turner et al., 2011). These studies failed to look at transition management processes as was being done by nurses at the time.

Another group of scholars was also noted to focus on transitions, but from long-term care facilities. Their studies, however, focused on transitions of mostly older adults from long-term care facilities to the community with Medicaid waiver programs (Meador et al., 2011; Robison et al., 2015; Robison et al., 2012). These studies broadly focused on

transitions in a broader context, looking at predictors and other factors that will ensure successful transitioning to the community (Arling et al., 2011; Arling et al., 2010).

Among this set of literature, there were inputs made from policy makers and advocates making a case for the older adult to age in their homes (Reinhard, 2012). There were also the voices of the critics, who felt such transitions were not feasible as states did not have set infrastructure for home and community-based services such as affordable housing, and were not as prepared (Fields et al., 2011). Despite this, transitions under the Medicaid waivers looked promising, as it offered intensive case management services and varied supports through its home and community-based services and supports (Kane, 2012). A critical gap noted in this set of literature was that these studies focused only on the older adult; even though young and middle-aged adults with chronic disabilities such as TBI also live in long-term care facilities.

In an attempt to bring their findings together, unique systematic synthesis of these three sets of data was conducted, and findings depicted a full scope of what transitioning from a healthcare setting entailed (Chapter 2). Transitioning was found to extend beyond care transitions. It broadly included two processes, psychological and a physical process, and involved both procedural and structural elements. In that study the term “care transitions” remained ambiguous and was a term I found difficult to understand or even explain. In conducting this study, the enlightenment of what transitioning is has occurred. Care transition is mainly the transition management processes revealed by the IPMTC. The disjoint in the literature has been bridged with the IPMTC, as it describes the broader transition process studied in rehabilitation science and among other scholars and also incorporates the transition management processes being considered by nurses as care

transitions. Undoubtedly, transitioning is a complicated process with many moving parts. Therefore, it is prudent to focus on all aspects, including the physical, psychological, and social issues of the process which the IPMTC is set to do.

Furthermore, through my reflection, I could not help but focus on how the outcome of transitioning was currently measured. Thirty-day readmission and the re-hospitalization rate is commonly used as the outcome measure of transitioning. This is understandable, as these measures have been directly associated with increased healthcare cost (Friedman & Basu, 2004). In doing so, however, the focus of transition outcome has shifted from the person to the organizations that we are indebted to. Yet as nurses, the care of the person is fundamental to our practice, as suggested by the four metaparadigms of nursing (Fawcett, 1984). Therefore, their wellbeing in this transition process must be a priority. Defining successful transition from the perspective of the individual with TBI, their family caregivers, professional caregivers, and community service providers was a first step in efforts to develop other measures reflective of a true meaning of successful transitioning, from the perspective of the individual and their families (see Figure 4). Also, the development of the IPMTC as a true person-centered approach to transitioning will help steer our focus back to the person.

Transitioning of the individual with TBI from the long-term care facility to community is a nursing process which should be led and orchestrated by nurses. Currently, under the Medicaid waiver program, the drive is towards a non-medical model (Bardo et al., 2014), even though the role of the nurse has been found to be significant across the continuum. It is time for a policy change to relegate back our role from social workers and take the lead role in the management of this process. The call by the ARN in



its white paper is undoubtedly laudable and a step in the right direction (Camicia et al., 2014). Even though the IPMTC is promising as earlier discussed, there is lots of work to be done to develop this theory further in other populations and across settings. Some of the current concepts and the definition of successful transitions will have to be conceptualized and operationalized in future studies.

### **Contributions to Scientific Knowledge**

This study has made significant contributions to scientific knowledge. The study explored the process of transitioning from a long-term care facility to residential group home in the community using a broad sample across the Commonwealth of Massachusetts. The study sample included the individual with TBI, their family caregivers, the professional caregivers, and community service providers, to represent essential stakeholders in this process. The voices of the policymakers were visibly absent as they lacked representation in this study.

Findings from the study bridges several important gaps in the scientific literature. This study is the first to look at the transitioning process of the individual with TBI from a long-term care facility to residential group homes to community in the United States. The IPMTC developed is also the first to place transition management within the context of a broader transition process. The IPMTC, though not the first to address person-centeredness in the transitioning process, is one that places emphasis on true person-centeredness and discusses key concepts of choice, human rights, personal needs, etc. (see Figure 5). Also, IPMTC is the first to describe relationship building through social and professional interactions as a transition management process. Through this study, the

definition of successful transitioning has been reported to bridge an earlier identified gap. This knowledge will lay a foundation for the development of other measures of transition outcome. Also, this study has described the nurse role in the process of transitioning. Such knowledge is also helpful to nursing disciplines in areas of education and policy making. Furthermore, this work provides a framework to develop interventions that help improve transition outcomes for the individual with TBI and their families.

### **Strengths and Limitations**

This study presents several strengths. The study was conducted across the Commonwealth of Massachusetts and was able to capture how such transitions are being managed broadly. Also, this study used a diverse sample to obtain a wide range of perspectives of relevant stakeholders to the process. These included the individual with TBI, the family caregivers, and the professional caregivers (occupational therapists, nurse, social workers, human service providers, and service coordinators). It also obtained perspectives from community services providers including residential home directors, residential home staff, and community- based occupational therapists. Overall, thirty-one individuals participated in this study; which is considered significant in a qualitative study. Having a large sample was helpful in reaching theoretical saturation and the development of grounded theory. To date, research had not focused on understanding the social processes engaged in during transition from long-term care setting to the community. Also, the definition of a successful transitioning to the community was unknown. However, through this study, these gaps have been bridged. The IPMTC developed, as earlier described, has given a full understanding of the

transitioning process by putting transition management processes or care transitions as referenced by nursing into a broader transitioning context. The IPMTC also identifies individual, process, and system factors that influence the process both positively and negatively. This information is needed to develop future interventions for successful transitioning from a healthcare setting to the community. Furthermore, the IPMTC as an emerging theory promises to have broad application for persons with chronic illnesses and disabilities, including TBI, and may apply to transitions of other rehabilitation patients. The use of an interdisciplinary team also broadens the applicability of this model to other disciplines engaged in transitioning and its management. Finally, the IPMTC looks at transition at both a macro state level and a micro organizational level, which further broadens its applicability across states.

As much as this study reports many strengths, it also has limitations. This study initially faced many obstacles in getting the necessary approvals to work with this vulnerable population due to the bureaucratic nature of working with a state agency. The inclusion of only three individuals with TBI was due to the significant difficulty encountered in getting the service coordinators to provide me with access to this population. Working with individuals with TBI was particularly challenging, since they had significant speech impairments and could not participate in a direct interview, although they engaged in observation sessions and interacted positively with the researcher. Furthermore, the professional caregivers interviewed do not transition only individuals with TBI, but also persons with other disabilities, which sometimes came through during our interviews and put to the question the specificity of this study to the TBI population. Initially, the study proposed to include day program sites, if participants

were attendees. However, all the individuals with TBI did not attend day programs and hence, were excluded from the study. To fully implement transitions under the IPMTC, there should be adequate funding which could be expensive, thus limiting its application at a micro (organizational) level.

### **Study Implication**

Transitioning is an important concept in nursing practice, because as nurses, we transition individuals on a daily basis from one healthcare setting to another, or from a healthcare setting to the community. Therefore, understanding the process of transitioning was a step in the right direction to further our understanding of this phenomenon. Findings from this study have broad applications in research, practice, education, and health policy.

### **Research**

The "it's all about the person" model of transitioning to the community (IPMTC) has significant impacts on nursing research. This emerging theory has revealed several assertions or hypotheses which are yet to be tested in future research studies. The IPMTC describes a detailed process, and therefore it is prescriptive and can serve as a framework to develop interventions through research. Even though the applicability may be specific to long-term care settings, it describes transition management process such as communication, coordination, relationship building, planning, and social engagement, which are universal concepts and can be applied across other settings. The effort to test its applicability across settings provides yet another opportunity for further research.

Again, the IPMTC identified many factors that influenced this transition process. The extent of the effect of these factors on the process and the correlations and associations between these factors is yet to be studied, again providing further opportunity for research. I proposed in my discussion of the findings that the IPMTC is an emerging nursing theory. Therefore, research is needed to develop it further to become an established theory. Also, as a nursing process, the stage of diagnosis needs to be developed further in research to systematically diagnose individuals' risks and put in appropriate plans to mitigate such risks in a nursing process.

Furthermore, this study defined a successful transitioning to community, and this finding creates research opportunities to develop a tool to measure outcomes that are reflective of the experiences of stakeholders in the process. The study also defined the role of the nurse and found, for example, that the perceived role of the nurse in the long-term care setting is absent or minimal. This also provides an opportunity for further research to explain this phenomenon.

### **Practice**

The findings of this study are as relevant in research as it is in practice. The IPMTC describes a process which is prescriptive for practice. It also elaborates on key elements of transition management, communication, coordination, team collaboration, relationship building, and social engagement, among others, which has direct application to practice. The IPMTC promises to provide a framework to guide transition processes across healthcare settings. As a person-centered process, the IPMTC provides a

framework to incorporate true person-centeredness into the practice of discharges from the health care setting to the community.

### **Policy**

The idea to transition individuals with TBI from long-term care facilities resulted because of policy changes at both the state and federal level, in an attempt to reduce healthcare cost. Exploring this process was a first attempt to document the effect of the Medicaid waiver program on the individuals who transitioned from their own perspectives and that of their families, professional caregivers, and community service providers. The study found significant individual, process, and systems and organizational factors that may be facilitators or barriers to the process. Such information is helpful in implementing policy changes to better improve the transition processes at both a state level and at an organizational level. The finding of suboptimal team collaboration among the team, for example, will require policy to effect immediate change to those processes. In addition, these findings could serve as a template for new policies within states that currently run Medicaid transition programs or those that may be interested in starting one.

The IPMTC also has the potential to be integrated into health systems and policies in specific long-term healthcare organizations. IPMTC is unique as it addresses transitions of individuals with TBI. Therefore, this model could fit the ARN vision on improving transition management of the rehabilitation patient and could be adopted as a framework to develop new policies that will guide their transition management processes in rehabilitation.

## **Education**

The IPMTC is an emerging nursing theory that can be made useful in nursing education and competency training on transition management. The IPMTC is both descriptive and prescriptive and can serve as a useful tool in education. As an example of the nursing process, the IPMTC can be used in practical ways to teach the nursing process to students, who often find it difficult to grasp the concept and dismiss the relevance of the nursing process in their practice. The study involved other disciplines and collaborating organizations, therefore education and training on transition management can extend outside of nursing to include service coordinators, residential group home staff, and community service providers.

## **Summary**

In this study, successful transitioning was defined as the positive outcomes of transitions. These outcomes were perceived by study participants as positive life changes, which included psychological and physical changes in the life of the individual with TBI. Successful transitioning was also defined subjectively and objectively in a process context. This finding was significant, as it serves as a first step to the development of other transition outcomes that are reflective of the individual's transition experiences. Also, in this chapter, the IPMTC model was discussed as an emerging nursing theory with precise definitions for the four metaparadigms of nursing, which are person, health, nurse, and the environment. The core phenomenon grounding the IPMTC is the concept of "it's all about the person," making it a true person-centered process. The core elements of person-centeredness, as discussed, included personal need, choice, human rights,

safety, and dignity, among others. Furthermore, the IPMTC was discussed as a nursing process because its' processes fit the four processes in the nursing process, which are assessment, planning implementation, and evaluation. How the IPMTC compares to Meleis's transition theory and other transition intervention models such as the CTI and the TCM was also discussed. Through this comparison, the unique features of the IPMTC, as the only model that describes transition management in the context of a broader transition process, was also discussed in areas of its similarities and differences.

Reflections on current findings place the IPMTC as a bridge connecting all three sets of transition studies and presents a comprehensive approach to addressing transitioning from a healthcare setting. A theory that places transition management within a broader context of a transitioning process makes it meaningful to develop interventions that are comprehensive and likely to work. Through this discussion, the IPMTC's potential for broad applicability was recognized, and its contribution to scientific knowledge cannot be underestimated. The strengths, as well as the limitations of this study, was also discussed. Finally, its implications for research, practice, policy, and education were also discussed.

### **Conclusion**

Successfully transitioning individuals with chronic illnesses and disabilities, including TBI, from a healthcare facility to the community is an essential goal for healthcare professionals and other stakeholders at both a macro state level and a micro organizational level. Effective transitioning management processes continued to elude researchers and healthcare providers, resulting in suboptimal transition outcomes. This



study aimed to explore the processes of transitioning individuals with TBI from a long-term care facility to residential group homes in the community, and develop a grounded theory. Using a constructivist grounded theory approach, the IPMTC was developed, and it is the first emerging nursing theory on transitioning that describes transitions from a long-term care facility to the community under a state Medicaid waiver program and emphasizes true person-centeredness. It is also the first to place transition management processes within a broader context of the transitioning process. In addition, IPMTC is the first emerging theory to show that transitioning is a nursing process. Findings of this study also suggest that the process of checking in, planning, relationship building through mutual interactions, and social engagement are transition management processes that have yet to be emphasized in current practice. The significance of this study as groundbreaking cannot be underestimated, as it is a new emerging nursing theory that postulates how to efficiently manage transitions of individuals with TBI from long-term care setting to the community.

Finally, until we consider transitioning from a long-term care facility to community as a complex person-centered process and approach it as a nursing process using key management tools such communication, checking-in, planning, team collaboration, coordination, relationship building, and social engagement; suboptimal outcomes such as high rates of 30-day readmissions will persist. Interventions using the IPMTC as a framework is thus being recommended.

## **APPENDICES**

## APPENDIX A

### LETTER OF SUPPORT FROM MASSACHUSETTS REHABILITATION COMMISSION



CHARLES D. BAKER  
GOVERNOR

KARYN E. POLITO  
LIEUTENANT GOVERNOR

MARYLOU SUDDERS  
SECRETARY

ADELAIDE OSBORNE  
COMMISSIONER

*The Commonwealth of Massachusetts*  
*Executive Office of Health and Human Services*  
*Massachusetts Rehabilitation Commission*  
*600 Washington Street*  
*Boston, MA 02111-1704*

(617) 744-3600  
1 (800) 245-6543  
Voice/TDD (617) 204-3888  
Fax (617) 227-1254

To Whom It May Concern:

On behalf of the Massachusetts Rehabilitation Commission (MRC), I am pleased to offer my enthusiastic support for Ms. Sylvia Abbeyquaye's proposed research "Returning to community: Transitioning Young and Middle Aged Adults with Traumatic Brain Injury (TBI) from Long-Term Care Facilities to Community". Since 1985, the Massachusetts Rehabilitation Commission has provided services to support the rehabilitation and recovery of individuals with traumatic brain injuries through the Statewide Head Injury Program and the Traumatic Brain Injury Waiver (a MassHealth Home and Community Based Services Medicaid Waiver program). Over the past 6 years the MRC has had increasing involvement with the Medicaid waiver programs through its work with the Acquired Brain Injury and Money Follows the Person (additional Home and Community Based Services waivers), and has helped Medicaid-eligible persons with acquired brain injury (ABI) move to the community and obtain community-based services.

Through our work, we are acutely aware of the importance of finding the best practices to support the transition of young and middle-aged adults from long term care institutions to the community, and believe that such transitions represent their best opportunity to improve their quality of life. We also believe that community care is an effective means of reducing healthcare costs to the State.

Ms. Abbeyquaye's proposed research promises to help us better understand the current process of transitioning to the community from the perspectives of persons with TBI, families, professional caregivers and community service providers. Since this study is congruent with our current efforts to successfully transition these vulnerable persons, we are pleased support her study. MRC commits to assist Ms. Abbeyquaye in connecting with our case management staff, service providers, and our client population. MRC will also provide support in the areas of providing access for data collection purposes.

In conclusion, we fully support the efforts of Ms. Abbeyquaye as she seeks external funding to support this important research study. We believe this study will provide new knowledge about the process of transitioning individuals with traumatic brain injury and further improve their transition outcomes.

Sincerely,

Adelaide N. Osborne  
Commissioner

## APPENDIX B

### UNIVERSITY OF MASSACHUSETTS AMHERST IRB APPROVAL LETTER



**University of Massachusetts Amherst**  
108 Research Administration Bldg.  
70 Butterfield Terrace  
Amherst, MA 01003-9242

**Research Compliance**  
**Human Research Protection Office (HRPO)**  
Telephone: (413) 545-3428  
FAX: (413) 577-1728

#### Certification of Human Subjects Approval

**Date:** June 20, 2017  
**To:** Sylvia Abbeyquaye, Nursing  
**Other Investigator:** Cynthia Jacelon, Nursing  
**From:** Lynnette Leidy Sievert, Chair, UMASS IRB

Protocol Title: "Return to Community"- The Process of Adults 18-65 years with Traumatic Brain Injury, Transitioning from Long-Term Healthcare Facilities to Community.  
Protocol ID: 2017-3821  
Review Type: EXPEDITED - NEW  
Paragraph ID:  
Approval Date: 06/20/2017  
Expiration Date: 06/19/2018  
OGCA #:

This study has been reviewed and approved by the University of Massachusetts Amherst IRB, Federal Wide Assurance # 00003909. Approval is granted with the understanding that investigator(s) are responsible for.

**Modifications** - All changes to the study (e.g. protocol, recruitment materials, consent form, additional key personnel), must be submitted for approval in e-protocol before instituting the changes. New personnel must have completed CITI training.

**Consent forms** - A copy of the approved, validated, consent form (with the IRB stamp) must be used to consent each subject. Investigators must retain copies of signed consent documents for six (6) years after close of the grant, or three (3) years if unfunded.

**Adverse Event Reporting** - Adverse events occurring in the course of the protocol must be reported in e-protocol as soon as possible, but no later than five (5) working days.

**Continuing Review** - Studies that received Full Board or Expedited approval must be reviewed three weeks prior to expiration, or six weeks for Full Board. Renewal Reports are submitted through e-protocol.

**Completion Reports** - Notify the IRB when your study is complete by submitting a Final Report Form in e-protocol.

**Consent form (when applicable)** will be stamped and sent in a separate e-mail. Use only IRB approved copies of the consent forms, questionnaires, letters, advertisements etc. in your research.

Please contact the Human Research Protection Office if you have any further questions. Best wishes for a successful project.

## APPENDIX C

### LETTER FROM THE DEPARTMENT OF DEVELOPMENTAL SERVICES REGARDING STUDY APPROVAL



Charles D. Baker  
Governor

Karyn E. Polito  
Lieutenant Governor

The Commonwealth of Massachusetts  
Executive Office of Health & Human Services  
Department of Developmental Services  
Research Review Committee

500 Harrison Avenue

Boston, MA 02118

Telephone: (508) 845-9111 EXT. 1021

Fax: (508) 792-7000

Marylou Sudders  
Secretary

June P. Ryder  
Acting Commissioner

July 21, 2017

Sylvia Abbeyquaye PhD (c) MFA, RN  
26 Oakcrest Road  
Holden, MA 01520

**RE: Return to Community – The Process of Adults 18 – 65 years with Traumatic Brain Injury,  
Transitioning from Long-Term Healthcare Facilities to Community. 2017-6**

Dear Dr. Abbeyquaye:

On July 18, 2017, the Research Review Committee reviewed your proposal of "Return to Community – The Process of Adults 18-65 years with Traumatic Brain Injury, Transitioning from Long-Term Healthcare Facilities to Community."

Pursuant to 115 CMR 10.01 "The Department (DDS) is authorized by M.G.L. c19B, §§ 1, 14 and 19 and M.G.L. c123B, §2 to regulate research activities concerning intellectual disability as defined..."

Your research proposal did not relate to people with intellectual disability, therefore it falls outside the scope of our authority and does not need to be reviewed by the DDS Research Review Committee.

Thank you for your attention in this matter.

Sincerely yours,

A handwritten signature in black ink, appearing to read "John C. Gearty Jr.".

John C. Gearty Jr.  
Assistant General Counsel and  
Chairperson  
Research and Review Committee

CC: Marianne Meacham - General Counsel

## APPENDIX D

### SCRIPTS FOR PARTICIPANT RECRUITMENT

#### SCRIPT FOR RECRUITMENT OF FAMILY CAREGIVER

Hello, my name is Sylvia Abbeyquaye and I am a doctoral candidate at the University of Massachusetts Amherst College of Nursing. I spoke to the DDS service coordinator for---  
- (Name of Individual with TBI) who indicated to me that you were his/her primary family caregiver. I am calling you to directly solicit your participation in my research study on transitioning individuals with Traumatic Brain Injury (TBI) from long term healthcare facilities to group homes in the commonwealth of Massachusetts under the Medicaid waivers. The purpose of this study is to understand how individuals with TBI, their families, professional caregivers and service providers manage the processes involved in such transitions and develop theory. Eligible participants for this study are individuals with TBI 18-65 years who transitioned from a long-term care facility to a group home under ABI or MFP Medicaid residential waiver programs. Family caregivers who are closely involved with the individual with TBI. Professional staff working with individual with TBI during transitioning to community and home and community-based service providers involved with transitioning under the ABI or MFP Medicaid residential waivers.

For your part as a family caregiver of an adult with individual with TBI who transitioned from a nursing home to the group home under the ABI/MFP Medicaid waiver program, you will be asked to participate in a one-hour interview session. A follow up interview of up to one hour may also be required later during the course of the study.

Participation in this study is voluntary and if you want more information and time to make this decision I do respect that.

Do you have any questions for me now?

As a family caregiver will you be willing to participate in this study? Please answer yes or no.

If you decide later that you will like to participate in this study, you may contact me via phone or email. My cell phone number is 508 361 8461 and my E-mail is

[sabbeyquaye@acad.umass.edu](mailto:sabbeyquaye@acad.umass.edu)

Thank you for your time.

## RECRUITMENT SCRIPT FOR GUARDIAN

Hello, my name is Sylvia Abbeyquaye and I am a doctoral student at the University of Massachusetts Amherst College of Nursing. I am conducting a research study on transitioning individuals with Traumatic Brain Injury (TBI) from long term healthcare facilities to group homes in the commonwealth of Massachusetts. I spoke to the DDS service coordinator for---- (Name of Individual with TBI) who indicated to me that you were his/her legal guardian. I am calling you to solicit his/her participation in this study. During the study, ---- (State name of individual with TBI) with your signed consent and his assent will be asked to participate in two 30 minutes interview sessions with researcher. He/she will be asked to share his/her experiences at the nursing home and his transition to the group home. Also, as part of the study, researcher will visit with Individual with TBI at his/her group home and day program to observe his/her interactions with friends and group home staff. Three such visits will be conducted during the course of this study each will be for about 2 hours. In the event that----- (name of individual with TBI) cannot participate meaningfully in an interview, he/she will only be asked to take part in the three observation sessions. Study will also require a review of some medical records such as discharge summaries, case manager notes, incident reports and caregivers' daily notes and logs. The entire study is anticipated to last for about 18 months.

If you are also the primary family caregiver, then I will also ask that you participate directly in this study. For your part as a family caregiver you will be asked to participate in a one-hour interview session. A Follow up interview of up to one hour may also be required later during the course of the study.

Participation in this study is voluntary and if you want more information and time to make this decision I do respect that.

Do you have any questions for me now?

If you agree as guardian that (name of Individual with TBI) can participate in this study, then I will mail you consent forms and a HIPAA authorization form that need to be signed and received prior to my initial visit with him/her. An assent will also be obtained from him as well at the initial courtesy visit prior to scheduling any interview.

Will you on behalf of---- (Name of individual with TBI) please be willing to allow participation in this study? Please answer yes or no.

As a family caregiver will you also be willing to directly take part in this study? Please answer yes or no.

If you decide later that you will like to participate in this study, you may contact me via phone or email. My cell phone number is 508 361 8461 and my E-mail is

[sabbeyquaye@acad.umass.edu](mailto:sabbeyquaye@acad.umass.edu)

Thank You for your time

## RECRUITMENT SCRIPT FOR INDIVIDUAL WITH TBI

Hello---- (State name of Individual with TBI), How are you? I spoke with----- Your case manager from DDS (State name of case manager) who told me you are a participant in the ABI/MFP program and have successfully moved from the nursing home to a group home. Is that right? My name is Sylvia Abbeyquaye and I am a doctoral student at the University of Massachusetts Amherst College of Nursing. I am doing a research study to find out how people with traumatic brain injury manage during their move from the nursing home to a group home. I am calling to ask you if you will be willingly to share your experience and be part of this study. Taking part in this study is voluntary. As part of the study I will ask you to answer some questions, I will visit you at your group home to spend time with you and observe what you do in the day and I will also ask to look through your medical records. If you want more information I will be glad to come visit with you at the group home, so we can talk more about the study. If you do not want to participate that is OK too and it will not affect your being in the ABI/MFP waivers in any way.

Do you have any questions for me now?

Will you please be willing to be a participant in this study? Please answer yes or no. If you want more time to think about it. I will call you again next week to find out if you have made a decision.

Thank you very much for your time



## RECRUITMENT SCRIPT FOR DDS SERVICE COORDINATORS

Hello, my name is Sylvia Abbeyquaye and I am a doctoral student at the University of Massachusetts Amherst College of Nursing. I am conducting a research study on transitioning individuals with Traumatic Brain Injury (TBI) from long-term healthcare facilities to group homes in the commonwealth of Massachusetts. As a service coordinator of ABI/MFP residential waivers, I am calling you to solicit your direct participation in this study and also to ask for your help in identifying individuals with TBI, their families and /or guardian under your care that will most likely want to participate in this study. Once identified I will reach out to them directly to solicit their participation in this study. During the course of this study I will also like to have an interview with you about how you manage the transition of individuals with TBI to community from the Long-term care. Participation in this study is voluntary and if you want more information and time to make this decision I do respect that.

Do you have any questions for me now?

Will you please be willing to be a participant in this study? Please answer yes or no

If you decide later that you will like to participate in this study, you may contact me via phone Tel: 508 361 8461 cell, or E-mail [sabbeyquaye@acad.umass.edu](mailto:sabbeyquaye@acad.umass.edu)

Thank You!

## APPENDIX E

### RESEARCH FLYERS FOR RECRUITING PROFESSIONAL CAREGIVERS



## **University of Massachusetts Amherst** **VOLUNTEERS WANTED FOR NURSING** **RESEARCH**

**Are you a Nurse, Social Worker, or Rehab professional (PT, OT, ST) working in a long-term healthcare facility or chronic hospital and has been involved in discharge planning and transitioning of individuals with TBI to group homes under the ABI or MFP Medicaid Waiver Program?**

**Are you 18 years and older?**

**Are you willing to talk about your experience working with individuals with TBI during their transitions to community under the Medicaid Waiver programs and how you have managed such transitions?**

**What do I have to do?** Each volunteer will be required to participate in a one hour in person interview session. The time and place is at your convenience. The interview is to explore the issues around the transitioning process. A Second interview may be necessary to follow up on emerging concepts or clarify some concepts which may come up from the first interview. The second interview may be over the phone and may be up to 30 minutes. Each participant will receive a \$20 gift card as a token of my appreciation for helping with this study.

**Who is doing the research?** Sylvia Abbeyquaye is a Registered Nurse and a PhD student at the College of Nursing at the University of Massachusetts at Amherst. Sylvia is developing a theory to understand the process of transitioning individuals with TBI 18-65 years from long-term care facilities or chronic hospital to community.

**How do I get involved?** To volunteer contact Sylvia Abbeyquaye by telephone at (508) 361 8461 or email her at [sabbeyquaye@acad.umass.edu](mailto:sabbeyquaye@acad.umass.edu). **THANK YOU!**

## APPENDIX F

### SCREENING CHECKLIST FOR INDIVIDUAL WITH TBI

#### SCREENING CHECK LIST

Pseudonym:

Age:

Are you a Traumatic Brain Injury Survivor? Yes ☐ No ☐  
Do you have a guardian? Yes ☐ No ☐  
Do you have a caregiver who will be willing to participate in this study? Yes ☐ No ☐

#### Kahn and Goldfarb Mental Status Questionnaire

1. What is the name of the place you are right now?
2. Where is it located? (Address)
3. What is today's date?
4. What is the month now?
5. What is the year?
6. How old are you?
7. When were you born? (Month)
8. When were you born? (Year)
9. Who is the President of the United States?
10. Who was the president before him?

**Kahn and Goldfarb Score**-----

#### Scoring key

- 0 – 2 errors no or mild impairment
- 3 – 8 errors moderate impairment
- 9 – 10 errors severe mental impairment

Kahn, R.L., Goldfarb, A. I., Pollack, M., & Peck, A. (1960). Brief objective measures for the determination of mental status in the aged. *American Journal of Psychiatry*, 117: 326-328

## APPENDIX G

### DEMOGRAPHIC QUESTIONNAIRES

#### DEMOGRAPHIC QUESTIONNAIRE FOR INDIVIDUAL WITH TBI AND GUARDIAN/ FAMILY CAREGIVER

Pseudonym: -----

Date of Interview: -----

Age: -----

Year of Brain Injury (if applicable): -----

Cause of Traumatic Brain Injury? -----

Relationship to individual with TBI (if applicable) -----

Gender:                      Male      ☐      Female      ☐      Other ☐-----

Race/ ethnicity: White (Non-Hispanic) ☐

Black/ African ☐

Asian ☐

Hispanic ☐

Other ☐ -----

Educational level:      Up to 8<sup>th</sup> grade ☐

High school ☐

Some college ☐

Bachelors ☐

Graduate degree ☐

Marital Status: Single/ Never Married ☐ Married ☐ Divorced ☐ Widowed ☐

DEMOGRAPHIC QUESTIONNAIRE FOR PROFESSIONAL CAREGIVERS/HCBS  
PROVIDERS

Pseudonym: ----- Date of Interview: -----

Age: ----- Name of Organization -----

Gender: Male ☐ Female ☐ Other ☐ -----

Race/ ethnicity: White (Non-Hispanic) ☐  
Black/ African ☐  
Asian ☐  
Hispanic ☐  
Other ☐ -----

Educational level: Up to 8<sup>th</sup> grade ☐  
High school ☐  
Some college ☐  
Bachelors ☐  
Graduate degree ☐

Profession /Occupation -----

What is your current position at the organization? -----

Length of years working with organization/agency: < 1 year ☐ 1-5 years ☐ > ☐ years

How long have you worked with individual with TBI? -----

## APPENDIX H

### CONSENT FORMS

#### CONSENT FOR PROFESSIONAL CAREGIVERS/COMMUNITY SERVICE PROVIDERS

**Consent Form for Participation in a Research Study**  
**University of Massachusetts Amherst**  
**Professional Healthcare and Community Service Providers Consent**

**Researcher(s):** Sylvia Abbeyquaye PhD(c) RN  
**Research Supervisor:** Cynthia Jacelon PhD  
**Study Title:** "Return to Community"- The Process of Adults 18-65 years with Traumatic Brain Injury, Transitioning from Long-Term Healthcare Facilities to Community

**1. WHAT IS THIS FORM?**

This form is called a Consent Form. It will give you information about the study so you can make an informed decision about participation in this research.

**2. WHO IS ELIGIBLE TO PARTICIPATE?**

To participate in this study, you must be an adult 18 years and older. You should be a professional healthcare provider (nurse, case manager, transitional care coordinator, social worker, neuropsychologists etc.) or a community service provider (staff of day program, group home, and other community programs) who participates in transitioning individuals (18-65 yrs.) with TBI from long term healthcare facilities to community.

**3. WHAT IS THE PURPOSE OF THIS STUDY?**

We are conducting this research to describe the process of transitioning home for individuals with TBI after living in a long term health care facility for at least 90 days. The objective of this study is to determine what this process of transitioning individual with TBI to community means to you as a healthcare professional/ community service provider and your client with TBI so as to develop new theory to inform practice.

**4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?**

The entire study will take about 18 months. Your part may consist of two interview sessions. The first interview will be in person at a time and place of your choice and will last for about an hour. The second interview will only be scheduled if researcher has new questions and/or seeks clarification of issues raised in the first interview. The second interview may be in person or over the phone. At the end of the study, if you agree, you may be re-contacted in person to see if the study findings match your experience. This meeting will be at a place of your choice and may last up to 30 minutes.

**5. WHAT WILL I BE ASKED TO DO?**

If you agree to take part in this study, once it has been determined that you have the experience we are looking for, the interview will be scheduled at a time and place convenient for you.

All interviews will be audio recorded. The session will be about an hour long. The interviewer will ask you to discuss broad questions to explore how you manage the process of transitioning individuals with TBI from the long term care facility to home. Other topics to be explored will include your role as a professional care provider in the process, barriers encountered in this process and the process of coordinating and managing the available community resources.



If you work closely and directly with individual with TBI as group home or day program staff, your interactions with individual will also be observed. Observation sessions may last up to 2 hours. 3 sessions will be conducted throughout entire study and at different times of day. You will be required to participate only when you are available on the day or time of the observation session. During such observations, your pictures may be taken to capture significant/memorable events. Fields notes will also be taken to record occurring events.

#### **6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?**

You may not directly benefit from this research; however, we hope that your participation in the study may help us describe the process of transitioning. Understanding this process will help us develop new theory that will guide practice. Such theory will help us develop efficient care coordination and case management models that help enhance the quality of life of individuals with TBI and their families.

#### **7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?**

There are no physical, economic or social risks to being in this study. However, if you find yourself getting distressed/upset about the questions being asked. You may ask to have researcher stop the interview. Researcher at his/her discretion may also stop the interview if any sign of distress is noted and offer support as appropriate.

#### **8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?**

The following procedures will be used to protect the confidentiality of your study records. You will be asked to choose a false name for this study to protect your identity. Researchers will keep all study records including audio files, notes, and any analyzed data, in a locked file cabinet or on a password protected computer. Research records will be labeled with your false name. A key that link your real name with your false name will be kept in a separate, secure location. The key and recordings will be destroyed 3 years after the end of the study. The transcripts may be used in future research on surviving brain injury. Only the members of the research staff will have access to the records. At the conclusion of this study, the researchers will publish and present their findings in professional journals and conferences. You will not be identified in any publications or presentations.

#### **9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THE STUDY?**

You will not receive any payment for taking part in this study but I will give you a \$20 dollars' gift card at the completion of the first interview as a token of my appreciation.

#### **10. WHAT IF I HAVE QUESTIONS?**

Take as long as you like before you make a decision about participating in this study. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, Sylvia Abbeyquaye at 508-361-8461 or [sabbeyquaye@acad.umass.edu](mailto:sabbeyquaye@acad.umass.edu) or my supervisor, Dr. Cynthia Jacelon at 413 687 4854 or [jacelon@nursing.umass.edu](mailto:jacelon@nursing.umass.edu).

If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or [humansubjects@ora.umass.edu](mailto:humansubjects@ora.umass.edu).

#### **11. CAN I STOP BEING IN THE STUDY?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.



## 12. WHAT IF I AM INJURED?

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subjects' research, but the study personnel will assist you in getting treatment.

## 13. SUBJECT STATEMENT OF VOLUNTARY CONSENT

When signing this form, I agree to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. In addition, please check the one that is consistent with your decision

- ☐ Agree to have my interview audio recorded and to have a summary of the recording used in research reports or publications without reference to my name affiliation or any identifying information
- ☐ I agree to be contacted at the end of the study to see if the findings of the study match my experience.
- ☐ I agree to have my picture taken while interacting with individual with TBI.
- ☐ Do not agree to have my picture taken while interacting with individual with TBI
- ☐ Do not agree to be either interviewed or observed and I also do not want my interview audio recorded (If this is your choice, you are no longer eligible to participate in this study. Thank you).
- ☐ A copy of this signed informed consent form has been given to me.

\_\_\_\_\_  
Participant Signature :

\_\_\_\_\_  
Print Name :

\_\_\_\_\_  
Date :

By signing below, I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

\_\_\_\_\_  
Signature of Person  
Obtaining Consent

\_\_\_\_\_  
Print Name:

\_\_\_\_\_  
Date:





# CONSENT FORM FOR FAMILY CAREGIVER

## Consent Form for Family Caregiver in a Research Study University of Massachusetts Amherst

**Researcher(s):** Sylvia Abbeyquaye PhD(c) RN,  
**Research Supervisor:** Cynthia Jacelon PhD  
**Study Title:** "Return to Community"- The Process of Adults 18-65 years with Traumatic Brain Injury, Transitioning from Long-Term Healthcare Facilities to Community

### 1. WHAT IS THIS FORM?

This form is called a Consent Form. It will give you information about the study so you can make an informed decision about participation in this research.

### 2. WHO IS ELIGIBLE TO PARTICIPATE?

To participate in this study, you must be an adult 18 years and older. You should also be a family member of an individual with TBI who is at least 18 years old and not more than 65 years old, survived a traumatic brain injury and lived at least 90 days in a long term healthcare facility and have returned back to the community. You should be willing to participate in this study and be able to understand and speak English to participate in an interview.

### 3. WHAT IS THE PURPOSE OF THIS STUDY?

We are conducting this research to describe the process of transitioning individuals with TBI from long term health care facility to the community. The objective of this study is to determine what this process of transitioning to community means to you as a family caregiver and to your family member with TBI so as to develop a new theory to inform practice.

### 4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?

The entire study will take about 18 months. Your part may consist of two interviews. The first interview will be in person at a time and place of your choice and will last for about an hour. The second interview will only be scheduled if researcher has new questions and/or seeks clarification of issues raised in the first interview. The second interview may be in person or over the phone. At the end of the study, if you agree, you may be re-contacted in person to see if the study findings match your experience. This meeting will be at a place of your choice and may last up to 30 minutes.

### 5. WHAT WILL I BE ASKED TO DO?

If it is determined by researcher that you fit the research criteria and you agree to take part in this study, an interview will be scheduled at a time and place convenient for you.

All interviews will be audio recorded. The first interview will be in person and take about an hour. The interview will be based on the broad question: Describe the processes involved in transitioning your family member from the long term care facility to home? Other topics to be explored will include your role in the process, barriers encountered in this process and the process of accessing available community supports. You and your family member will be interviewed separately. You may skip any question you would rather not answer.

After the recording is transcribed, the interviewer will contact you to arrange a second interview to follow up on questions from the first interview and ask about any new topics that may have come up from the first interview.

University of Massachusetts Amherst-IRB	
(413) 545-3428	
Approval Date: 06/20/2017	Protocol #: 2017-0021
Valid Through: 06/18/2019	
IRB Signature: _____	

This study does not intend to have you participate in an observation session, however, your loved one will be observed as part of this study. If you happen to be present at the time of this observation session, your interactions with him/her may be recorded and your picture may be taken during such interactions to capture important and memorable event.

#### **6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?**

You may not directly benefit from this research; however, we hope that your participation in the study may help us understand the process of transitioning individuals with TBI. The finding of this study may help develop new care coordination and case management models for practice. Such models will help identify and coordinate the most appropriate services and supports needed by families and the individual with TBI during their move from the long term care facility to community. This will contribute to efforts aimed at improving their quality of life and wellbeing.

#### **7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?**

There are no physical, economic or social risks to being in this study. There is a slight chance that the topics discussed may be upsetting to you since you will be asked to talk about events before and after the brain injury of your family member. You do not have to answer any question you choose not to talk about. If you get upset during the interview:

1. The interview will be paused.
2. Emotional support will be provided immediately by the interviewer who is a Registered Nurse and an expert in working with individuals with brain injury and their caregivers.
3. You will be asked if you want to continue with interview.
4. If there is a continued need for emotional and psychological support, you will be given a list of agencies in the community that you can contact for counseling and further support.
5. Interviewer will call you within 24 hours of such incidents to check on you.

#### **8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?**

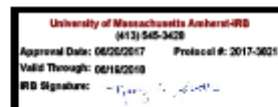
The following procedures will be used to protect the confidentiality of your study records. You will be asked to choose a false name for this study to protect your identity. Researchers will keep all study records including audio files, notes, and any analyzed data, in a locked file cabinet or on a password protected computer. Research records will be labeled with your false name. A key that link your real name with your false name will be kept in a separate, secure location. The key and recordings will be destroyed 3 years after the end of the study. The transcripts may be used in future research on surviving brain injury. Only the members of the research staff will have access to the records. At the conclusion of this study, the researchers will publish and present their findings in professional journals and conferences. You will not be identified in any publications or presentations.

#### **9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THE STUDY?**

You will not receive any payment for taking part in this study but I will give you a \$20 dollars' gift card at the completion of the first interview as a token of my appreciation.

#### **10. WHAT IF I HAVE QUESTIONS?**

Take as long as you like before you make a decision about participating in this study. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, Sylvia Abbeyquaye at 508-361-8461 or [sabbeyquaye@acad.umass.edu](mailto:sabbeyquaye@acad.umass.edu) or my supervisor, Dr. Cynthia Jacelon at 413 687 4854 or [jacelon@nursing.umass.edu](mailto:jacelon@nursing.umass.edu).



If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or [humansubjects@ora.umass.edu](mailto:humansubjects@ora.umass.edu).

#### 11. CAN I STOP BEING IN THE STUDY?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

#### 12. WHAT IF I AM INJURED?

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subjects' research, but the study personnel will assist you in getting treatment.

#### 13. SUBJECT STATEMENT OF VOLUNTARY CONSENT

When signing this form, I agree to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. In addition, please check the one that is consistent with your decision

- ☐ Agree to have my interview audio recorded and to have a summary of the recording used in research reports or publications without reference to my name affiliation or any identifying information
- ☐ I agree to be contacted at the end of the study to see if the findings of the study match my experience.
- ☐ I agree to have my picture taken while interacting with individual with TBI.
- ☐ Do not agree to be either interviewed or observed and I also do not want my interview audio recorded or my picture taken during the observation. (If this is your choice, you are no longer eligible to participate in this study. Thank you for your time).

A copy of this signed informed consent form has been given to me.

\_\_\_\_\_  
Participant Signature :

\_\_\_\_\_  
Print Name :

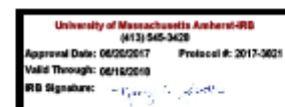
\_\_\_\_\_  
Date :

By signing below, I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

\_\_\_\_\_  
Signature of Person  
Obtaining Consent

\_\_\_\_\_  
Print Name:

\_\_\_\_\_  
Date:



## CONSENT FOR INDIVIDUAL WITH TBI/GUARDIAN

### Consent Form for Participation in a Research Study University of Massachusetts Amherst Individual with Traumatic Brain Injury/Guardian

**Researcher(s):** Sylvia Abbeyquaye PhD(c)

**Research Supervisor:** Cynthia Jacelon PhD

**Study Title:** "Return to Community"- The Process of Adults 18-65 years with Traumatic Brain Injury, Transitioning from Long-Term Healthcare Facilities to Community

#### 1. WHAT IS THIS FORM?

This form is called a Consent Form. It will give you information about the study so you can decide if you want to take part in this research.

#### 2. WHO CAN PARTICIPATE?

To participate in this study,

- You must be at least 18 years old and not more than 65 years old.
- You must have survived a traumatic brain injury and lived at least 90 days in a nursing home.
- You must be someone who has moved to a group home from a nursing home.
- You must be able to sign this consent form if you are your own guardian.
- Your guardian or power of attorney should sign this form on your behalf, if they are legally responsible for signing such papers.

#### 3. WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to describe how individuals with traumatic brain injury work out their move from the nursing home to the group home. The goal of this study is to understand what this move means to you and how it impacts your way of life.

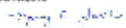
#### 4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?

- The entire study will take about 18 months to complete but your total involvement in this study will be up to 8 hours.
- Study will comprise of interviews and/or participant observations.
- Interviews will take place at your group home and will be completed in two 30 minutes' sessions.
- The observation session may be up to 6 hours during the full course of the study and may take place at your group home or at the day program site.
- If you are unable to participate verbally in an interview, researcher with your permission may only observe your social interactions and activities.
- A few pictures will be taken of you during such observations.

#### 5. WHAT WILL I BE ASKED TO DO?

If you agree to take part in this study and it has been determined that you have met the standards we are looking for to take part in this study;

- An interview will be scheduled at a time convenient to you and group home staff.
- All interviews will be audio recorded.
- Interviews will be in person and will be completed in two 30 minutes' sessions and on different days.
- The interview will be based on the broad question: Tell me how your move from the nursing home to the group home has worked out for you.

University of Massachusetts Amherst-IRB	
(413) 545-3438	
Approval Date: 05/09/2017	Protocol #: 2017-3821
Valid Through: 05/18/2018	
IRB Signature: 	



- You will be interviewed separately from your family member and/or group home staff.
- You may skip any question you would rather not answer and you may stop interview at any time.
- At some point after the interview, the researcher may contact you again for any follow-up questions.
- In addition to or in place of an interview, researcher will visit to spend time with you at the group home and/or at your day program.
- During such visits, researcher with your permission will observe your social interactions with your friends and staff and will take notes as well as pictures.
- Three such visits will occur during the course of this study and they will last for up to 2 hours. Sessions will be at different times of day and on different occasions.
- If you are unable to verbally participate in an interview, you will only be asked to participate in 3, two hour observation sessions along the course of the study.
- Some of your medical records including case manager's notes, discharge summaries, behavior logs, incident reports and staff notes may also be reviewed as part of this study once you agree to sign a HIPAA authorization form. This HIPAA authorization form allows researcher to have access to your records solely for research purpose.

#### 6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?

You may or may not find direct benefit from participating in the study, but some people find it interesting to talk to others about their experiences. We hope that your participation in the study may help us understand the process of transitioning individuals with TBI from nursing homes. The finding of this study may further help in identifying and providing appropriate services and supports needed by individuals with TBI and their families as they move from the nursing home to the community.

#### 7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?

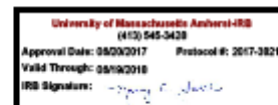
There are no physical, economic or social risks to being in this study. There is a slight chance that the topics discussed may be upsetting to you since you will be asked to talk about events before and after your brain injury. You do not have to answer any question you choose not to talk about. If you get upset during the interview:

- The interview will be paused
- Emotional support will be provided immediately by the interviewer who is a Registered Nurse and an expert in working with individuals with brain injury and their caregivers
- You will be asked if you want to continue with interview.
- If there is a continued need for emotional and psychological support, with your agreement, we will offer your staff or house manager options as to where you might be able to talk with someone further about things that have upset you.
- Interviewer will call you within 24 hours of such incidents to check on you.

#### 8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?

To protect your privacy, researchers will asked that:

- You choose a false name to be used during the study to protect your identity.
- Your study records including audio files, pictures, notes, and any analyzed data, will be kept in a locked file cabinet or on a password protected computer.
- Your research records will be labeled with your false name.
- A key that link your real name with your false name will be kept in a separate and secure location.



- The key and recordings will be destroyed 3 years after the end of the study.
- The written copies of your interviews may be used in future research on surviving brain injury. Only the members of the research staff will have access to such records.
- At the conclusion of this study, the researchers will publish and present their findings in professional journals and conferences. Your real identity by name will not be used in any publications or presentations about the study.

#### 9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THE STUDY?

You will not receive any payment for taking part in this study but I will give you a \$20 gift card as a token of my appreciation after your initial interview or observation session.

#### 10. WHAT IF I HAVE QUESTIONS?

Take as long as you like before you make a decision about participating in this study. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, Sylvia Abbeyquaye at (508)361-8461 or [sabbeyquaye@acad.umass.edu](mailto:sabbeyquaye@acad.umass.edu) or my supervisor, Dr. Cynthia Jacelon at (413)545-9576 or [jacelon@nursing.umass.edu](mailto:jacelon@nursing.umass.edu).

If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or [humansubjects@ora.umass.edu](mailto:humansubjects@ora.umass.edu)

#### 11. CAN I STOP BEING IN THE STUDY?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

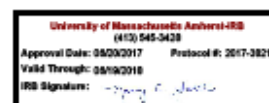
#### 12. WHAT IF I AM INJURED?

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subjects' research, but the study personnel will assist you in getting the help you need.

#### 13. SUBJECT STATEMENT OF VOLUNTARY CONSENT

When signing this form, I agree to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. In addition, please check the one that is consistent with your decision

- ☐ Agree to have my interview audio recorded and to have a summary of the recording used in research reports or publications without reference to my name affiliation or any identifying information
- ☐ I agree to be observed for up to 6 hours during the course of study in my group home and/or day program to record my daily activities and interactions with staff and peers.
- ☐ I agree to have my picture taken as I am being observed.
- ☐ I agree to have my medical records documents reviewed as part of this study and I have agreed to sign a HIPAA authorization form.



- ☐ I agree to be contacted at the end of the study to see if the findings of the study match my experience
- ☐ I do not agree to have my medical records and any other documents reviewed for this study.
- ☐ I do not agree to be either interviewed or observed and I also do not want my interview audio recorded or my picture taken during the observation. (If this is your choice, you are no longer eligible to participate in this study. Thank you for your time).
- ☐ A copy of this signed Informed Consent Form has been given to me.

\_\_\_\_\_  
Participant/ Guardian Signature:

\_\_\_\_\_  
Print Name:

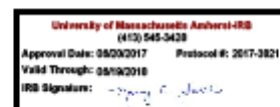
\_\_\_\_\_  
Date:

By signing below, I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

\_\_\_\_\_  
Signature of Person  
Obtaining Consent

\_\_\_\_\_  
Print Name:

\_\_\_\_\_  
Date:



## APPENDIX I

### ASSENT FORM FOR INDIVIDUAL WITH TBI

**Project Title:** “Return to Community”- The Process of Adults 18-65 years with Traumatic Brain Injury, Transitioning from Long-Term Healthcare Facilities to Community

**Researcher(s):** Sylvia Abbeyquaye PhD(c)

**Research Supervisor:** Cynthia Jacelon PhD

We want to tell you about a research study we are doing. A research study is a way to learn more about something. We would like to find out more about how your move from the nursing home to the group home was like. You are being asked to join the study because you survived a brain injury as an adult and lived in the nursing home for a while before moving to your group home.

If you agree to join this study, you will be asked to sit down two times with the researcher for about 30 minutes each time. Researcher will ask you several questions about your move from the nursing home. Also, the researcher will visit you at your group home and day program just to observe what you do and how you relate to your friends and the people who take care of you. Three such visits will be done on different days and each visit will be about 2 hours. Researcher will also read some information the nurses and staff have written about you and take notes.

If you agree to this study but feel you cannot sit to talk to researcher due to speech or other problems, researcher will only visit to observe what you do and how you relate to your friends and the people who take care of you.

Your family and guardian know about this study and that we are asking if you would like to be part of it.

There are some things about this study you should know. You will be asked how your injury happened and this could make you uncomfortable or can be difficult for you.

Not everyone who takes part in this study will benefit. A benefit means that something good happens to you. We think that we may learn something that will help other people who survive a brain injury be able to move from the nursing home back to their community.

You do not have to join this study. It is up to you. You can say okay now and change your mind later. All you have to do is tell us you want to stop. No one will be mad at you if you don't want to be in the study or if you join the study and change your mind later and ask to stop.



Before you say **yes or no** to being in this study, we will answer any questions you have. If you join the study, you can ask questions at any time. Just tell your caregiver or the researcher that you have a question.

If you want to be in this study, please write your name below.

Participant Name \_\_\_\_\_

Date \_\_\_\_\_

Name of Person obtaining assent \_\_\_\_\_

Date \_\_\_\_\_

## APPENDIX J

### HIPPA AUTHORIZATION FORM FOR INDIVIDUAL WITH TBI

<b>Participant's Full Name</b>	<b>Participants' Social Security Number (optional)</b>
--------------------------------	--

<b>Address</b>	<b>Participant's Date of Birth</b>
----------------	------------------------------------

<b>City, State Zip Code</b>	<b>Participant's Telephone Number</b>
-----------------------------	---------------------------------------

I hereby authorize use or disclosure of protected health information about me as described below.

1. The following specific person/class of person/facility is authorized to use or disclose information about me solely for research purpose

2. The following person (or class of persons) may receive disclosure of protected health information about me solely for research purpose:

**His/her/ Name**

**Address**

**City, State Zip Code**

3. The specific information that should be disclosed is  
☐ Discharge planning related documentation and transition notes from Nursing Home/Rehab facility  
☐ service coordinator notes and all transition related notes and records  
☐ Documentation or staff notes obtained during entire stay at group home included but not limited to hospital discharge summaries, current medication list, incident reports and behavior monitoring log.  
☐ Documentation or staff notes obtained since being admitted to day program included but not limited to activity log, incident reports and behavior monitoring log.

**UNLESS YOU SIGN HERE, NO INFORMATION ABOUT ALCOHOL/SUBSTANCE ABUSE, HIV/AIDS, OR MENTAL HEALTH WILL BE DISCLOSED:**

**YES, DISCLOSE THIS INFORMATION \*** \_\_\_\_\_

**NO, DO NOT DISCLOSE THIS INFORMATION \*** \_\_\_\_\_

4. I understand that the information used or disclosed may be subject to re-disclosure by the person or class of persons or facility receiving it and would then no longer be protected by federal privacy regulations.
5. I may revoke this authorization by notifying researcher in writing of my desire to revoke it. However, I understand that any action already taken in reliance on this authorization cannot be reversed, and my revocation will not affect those actions.

6. My purpose/use of the information is for understanding how you and your professional caregivers and home and community-based staff manage your move from the nursing home to the community in a research study.
7. This authorization expires at the end of study.

**THIS FORM MUST BE FULLY COMPLETED BEFORE SIGNING – note that signature is required in two places. \***

<hr style="border: 0; border-top: 1px solid black; margin-bottom: 5px;"/> <p style="text-align: center;"><b>Signature of Individual*</b> (The person about whom the information relates)</p>	<hr style="border: 0; border-top: 1px solid black; margin-bottom: 5px;"/> <p style="text-align: center;"><b>Date of Individual's Signature</b></p>	<hr style="border: 0; border-top: 1px solid black; margin-bottom: 5px;"/> <p style="text-align: center;"><b>Date of Birth</b></p>
<p><i>OR, if applicable –</i></p>		
<hr style="border: 0; border-top: 1px solid black; margin-bottom: 5px;"/> <p style="text-align: center;"><b>Signature of Guardian or Authorized Person</b></p>	<hr style="border: 0; border-top: 1px solid black; margin-bottom: 5px;"/> <p style="text-align: center;"><b>Date of Guardian's/ Authorized Person's Signature</b></p>	<hr style="border: 0; border-top: 1px solid black; margin-bottom: 5px;"/> <p style="text-align: center;"><b>Description of Authority to Act for the Individual</b></p>

*A copy of this completed, signed and dated form must be given to the Individual or other signatory.*

## APPENDIX K

### INTERVIEW SCHEDULES

#### INTERVIEW SCHEDULE FOR FAMILY CAREGIVER

**This interview guide does not list specific questions but provides cues for the PI to use while engaging in conversation with the participant. It is anticipated that by the conclusion of this interview, all topics listed below will have been discussed. At the discretion of the PI, Interview may be stopped at any time when there is evidence of emotional or psychological stress.**

Tell me how you felt when your family member was living in the nursing home?

As a family caregiver, what does his/her move back to the community mean to you?

Tell me what encouraged the move of your family member from the nursing home to the group home after having lived there for so long?

Describe your role as a family caregiver in this process of transition to the community if any?

Please describe in detail how you managed the transitioning of your family member to the group home from the long-term care facility?

Could you please describe the discharge planning processes involved with this transition?

Would you say your family member was adequately prepared by the transition staff for his/her move back to community? Please Explain.

How did the support given by staff during this process contribute to the success of the transitioning to the community if any?

Describe the role the nurse played in transitioning your family member to the community if any?

Can you please tell me about the community services your family member has been receiving since he/she moved to the community?

Describe the process family have had to go through in accessing these services?

Which of these community services in your opinion have contributed largely to the wellbeing of your family member in the community? Please explain.

How would you describe the social life of your loved one since his return to the community?

What social networks and supports are available to your loved one since his return to the community?

Tell me how these social relationships and supports have influenced the health and wellbeing of your loved one in the community?

Tell me how such relationships have helped with his/her process of transitioning from the nursing home?

How has your relationship with ----- (name of loved one) helped in his/her transitioning from the nursing home to the group home?

Describe some of the difficulties or setbacks your family has faced during this process of transitioning from long term care to community?

What would you like to be done differently in this process of moving back to the community?

How will you define a successful transition to community?

Generally, would you say the move of your family member back to the community have been successful? Please explain.

## INTERVIEW SCHEDULE FOR PROFESSIONAL CAREGIVERS AND COMMUNITY SERVICE PROVIDERS

**This interview schedule does not list specific questions but provides cues for the PI to use while engaging in conversation with professional caregivers and community service providers. It is expected that by the conclusion of this interview, all topics listed below will have been discussed. At the discretion of the PI, discussions may be stopped at any time when there is evidence of emotional distress.**

Discuss the processes involved in transitioning individuals with TBI from long term care facility to the community?

Discuss how this transition process means to you as a professional healthcare provider or community service provider?

Describe what you envision as your role in this process of transitioning?

What are the key elements needed in transitioning individuals with TBI from long term care facility to the community? How is this different from other populations?

In your opinion, do you need any specialized skill or training in transitioning individuals with TBI to community? Explain.

What are the challenges you face in managing the transitioning of individuals with TBI to the community?

Discuss the processes involved in accessing and coordinating community services? What could be done differently if any?

Which of these community services in your opinion have contributed largely to the success of the return of your client to the community? Please explain

What would you like to be done differently in this process of transitioning to the community?

Generally, would you say the process of transition from long term care facility to the community have been successful? Explain

How will you define a successful transition to community from long term care healthcare facility?

How do you manage the social activities of your clients in the group home settings or day program?

Describe the impact of social networking on the transition success of your clients?

What social networks and supports are available to your client since his return to the community?

Tell me how these social relationships and supports have influenced the health and wellbeing of your client in the community?

Tell me how such relationships have helped with his/her process of transitioning from the nursing home?

Tell me what you envision as your role or responsibility in this social network if any?

## INTERVIEW SCHEDULE FOR INDIVIDUAL WITH TBI

**This interview guide does not list specific questions but provides cues for the PI to use while engaging in conversation with the participant. It is anticipated that by the conclusion of this interview, all topics listed below will have been discussed.**

**Interview will be conducted in two sessions. At the discretion of the PI, Interview may be stopped at any time when there is evidence of emotional distress.**

Tell me how it felt like living in the nursing home?  
What does moving back to this group home mean to you?  
How different does it feel living here compared to living in the nursing home?  
Tell me why you decided to move from the nursing home after having lived there for so long?  
Describe how you were able to move out of the nursing home to this home?  
Please tell me if you well prepared by the staff for your move to this home?  
Please tell me what the staff did for you during that time?  
Tell me how you spend your day whist being home?  
Tell me some of the things you able to do with your friends and family since you left the nursing home?  
Who are the people most important to you?  
How are they important?  
How have these people helped you in your move from the nursing home?  
Tell me how you get along with your family?  
Tell me how you get along with your caregivers?  
Tell me how you get along with your friends?  
Describe the role your nurse played in getting you back to the community if any?  
Can you please describe the services you have been receiving since you moved to this home?  
Describe the process you have had to go through in getting these services?  
Which of these services would you say have helped you most? Please explain.  
Describe some of the problems you have faced during your move back to the community?  
What would you like to be done differently?  
Please tell me if your move to the community have been successful? Explain.

**APPENDIX L**  
**PARTICIPANT OBSERVATION SCHEDULE**

Date: ----- Start Time: ----- End Time-----

Setting: ----- Observer: -----

Participant: -----

**Observation Contents**

*Setting Characteristics:*

*Participant Characteristics:*

*Participant Activity and Behavior:*

*Interaction with others:*

*Reflections on Observation.*



## **APPENDIX M**

### **DOCUMENT REVIEW GUIDE**

Case notes, progress notes, incident reports and nurses note of participants with TBI will be reviewed paying attention to the following key words and themes

Teaching/ Education

Medication management

Medication reconciliation

Falls

Family involvement/ support

Community participation

Care transitions

Care coordination

Access to community services

Readmission

Re-hospitalization

Vocational Rehabilitation/ employment

Emergency Room (ER)/ Emergency Department (ED) visits

Behavior Management /Counselling

Doctor's Appointments and specialist consultation

Quality of life

## APPENDIX N

### RESEARCH ACTIVITY LOG

Activity	Date	Time	Participant
Int. 1	8/31/17	3:30pm-4:21pm	DDS service coordinator
Int. 2	8/31/17	4:30pm-5:27pm	DDS service coordinator
Int. 3	9/5/17	11:30am-11:57am	DDS service coordinator
Int. 4	9/5/17	1:00pm- 1:34pm	DDS service coordinator
Int. 5	9/5/17	1:55pm-2:35pm	DDS service coordinator
Int. 6	9/5/17	2:55pm-3:50pm	DDS service coordinator
Int. 7	9/7/17	4:07pm-5:15pm	DDS service coordinator
Int. 8	9/12/17	10:00am-11:43am	CSP-Transition coordinator
Int. 9	9/12/17	10:00am-11:43am	CSP-Options counsellor
Int. 10	9/12/17	10:00am-11:43am	CSP- Transition director
Int.11	9/15/17	3:15pm-4:02pm	DDS service coordinator
Doc. Review	9/17/17	2:11pm-3:47pm	Researcher
Int.12	9/21/17	1:06pm-1:43pm	Social worker
Int. 13	9/23/17	2:33pm-3:39pm	DDS service coordinator
Int.14	10/6/17	10:12am-10:47am	Residential group home director
Residential Home Tour	10/6/17	10:55am-11:20am	Research and staff
Int.15	10/10/17	1:31pm- 2:27pm	Social Worker
Int.16	10/18/17	10:30am-11:17am	Social Worker
Int.17	10/19/17	3:40pm- 4:13pm	Social worker
Int.18	11/6/17	1:30pm-2:02pm	CSP-Occupational therapist
Int.19	11/6/17	1:30pm-2:02pm	MAB director OT
Int.20	11/6/17	1:30pm-2:02pm	Community OT
Int.21	11/6/17	1:30pm-2:02pm	Community OT
Transition Meeting Observation	11/13/17	10:00am-12:00pm	Research and collaborative team
Int.22	11/21/17	2:00pm-3:05pm	Family caregiver
Part. Intro Visit.	11/28/17	10:30am-11:30am	Individual with TBI
Int.23	11/30/17	2:30pm-4:15pm	Family caregiver
Int.24	12/5/17	10:30am-11:15am	Individual with TBI
Part. Obsv.	12/5/17	10:30am-2:10pm	Individual with TBI
Int.25	12/5/17	2:15pm-2:48pm	Residential staff
Doc. Review	12/5/17	3:00pm-4:15pm	Researcher
Part. Intro visit	12/8/17	1:00pm-1:45pm	Individual with TBI
Residential Home Tour	12/12/17	10:30am-11:00am	Research and staff

Int.24	12/12/17	11:10am- 12:20pm	Residential program director
Part. Obsv.	12/14/17	4:15pm-6:00pm	Individual with TBI
Part. Obsv.	12/19/17	10:00am-2:15pm	Individual with TBI
Part. Intro visit	1/19/18	10:45am-11am	Individual with TBI
Int.25	1/19/18	11:00am-12:15pm	Family caregiver
Part. Obsv.	1/19/18	12:30pm-4:00pm	Individual with TBI
Doc. review	1/19/18	4:05pm-6:15pm	Researcher
Int.26	1/23/18	11:00am-12:15pm	DDS service coordinator
Part. Obsv	1/24/18	10:30am-3:00pm	Individual with TBI
Int.26	1/30/18	1:30pm-2:30pm	DDS nurse
Part. Obsv.	2/1/18	2:18pm-4:45pm	Individual with TBI
Doc. review	2/1/18	4:50pm-6:30pm	Researcher

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## **APPENDIX O**

### **GUIDELINES FOR BEHAVIOR INTERVENTION**

For Behavioral Distress

1. Participants identified with behavioral tendencies must be interviewed with staff presence to ensure safety of both participant and PI.
2. In the event of any behavioral distress, the interview session must be stopped before any behaviors escalate.
3. During intense behavioral outburst, PI must revert to group home staff for appropriate behavioral management and interventions per their protocol.

## **APPENDIX P**

### **GUIDELINES FOR PROVIDING EMOTIONAL SUPPORT**

If researcher/interviewer notes any sign of distress (sadness, anger, agitation);

1. The interview will be paused/stopped.
2. Emotional support will be provided within the scope of nursing practice.
3. Interviewer will assess situation and ask if participant want to continue with interview as appropriate.
4. If there is a continued need for emotional and psychological support, interviewer will give a list of identified resources in the community that offer counseling and/or other support to participant.
5. A courtesy call will be placed 24 hours after such instances to check on how participant is feeling.

## APPENDIX Q

### LIST OF COMMUNITY RESOURCES

In case of any emotional distress, you may seek added support from the agencies listed below:

Organization	Tel No:
Brain Injury Association	1-800-242-0030/ 508-475-0032
Carson Center for TBI Services/ Springfield	413-747-3700
Advocates, Inc. /Framingham	508-628-6300
North East Health Services / Taunton	508-880-6666

## APPENDIX R

### CITI TRAINING CERTIFICATE OF COMPLETION

#### COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)

##### HUMAN RESEARCH CURRICULUM COMPLETION REPORT

Printed on 09/21/2014

LEARNER	Sylvia Abbeyquaye (ID: 4409911) 26 oakcrest rd Holden MA 01520 US
DEPARTMENT	nursing
PHONE	508 361 8461
EMAIL	sabbeyquaye@acad.umass.edu
INSTITUTION	University of Massachusetts Amherst
EXPIRATION DATE	09/20/2019

#### GROUP 2 SOCIAL AND BEHAVIORAL RESEARCH INVESTIGATORS AND KEY PERSONNEL

COURSE/STAGE:	Basic Course/1
PASSED ON:	09/21/2014
REFERENCE ID:	14107983

REQUIRED MODULES	DATE COMPLETED
Introduction	09/21/14
History and Ethical Principles - SBE	09/21/14
Defining Research with Human Subjects - SBE	09/21/14
The Regulations - SBE	09/21/14
Assessing Risk - SBE	09/21/14
Informed Consent - SBE	09/21/14
Privacy and Confidentiality - SBE	09/21/14
Records-Based Research	09/21/14
Research With Protected Populations - Vulnerable Subjects: An Overview	09/21/14
Conflicts of Interest in Research Involving Human Subjects	09/21/14
Unanticipated Problems and Reporting Requirements in Social and Behavioral Research	09/21/14
University of Massachusetts Amherst	09/21/14

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Program course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiler Ph.D.  
Professor, University of Miami  
Director Office of Research Education  
CITI Program Course Coordinator

## **APPENDIX S**

### **CURRICULUM VITAE**

#### **SYLVIA K. ABBEYQUAYE**

Doctoral Candidate, College of Nursing  
University of Massachusetts Amherst  
Amherst, MA 01003  
Phone: 508 361 8461  
Email: [sabbeyquaye@acad.umass.edu](mailto:sabbeyquaye@acad.umass.edu)

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#### **RESEARCH INTERESTS**

Transitions of Care, Community Integration, Transcultural and Global Nursing,  
Immigrant Health, Family Research, Community Engagement and Participatory Research

#### **EDUCATION**

University of Massachusetts Amherst MA                      PhD Graduation Expected 9/1/18

Dissertation Title: "IPMTC"- An Emerging Nursing Theory on Transitioning Individuals  
with Traumatic Brain Injury from Long-Term Care Facility to the Community under  
Medicaid Waiver Programs.

University of Massachusetts Amherst, Amherst, MA      BS 2004, Nursing

Clark University, Worcester, MA                      MPA, 2002, Public Administration

Kwame Nkrumah University of Science and Technology, Kumasi, Ghana      BSc Hon 1998, Biochemistry

#### **AWARDS AND HONORS**

May 2016 Clinical Scholar Award, University of Massachusetts, Amherst  
May 2004 Deans Award for Clinical practice, University of Massachusetts, Amherst

#### **LICENSURE/CERTIFICATION**

06/2004 to present. Registered Nurse, Massachusetts Board of Nursing. License no:  
261002

#### **PROFESSIONAL MEMBERSHIPS**

2017-Present Eastern Nursing Research Society



2015 –Present Brain Injury Association of Massachusetts (BIA-MA)  
2014- Present. Association of Rehabilitation Nurses  
2004 –Present. Sigma Theta Tau, Beta Zeta At large Chapter

## **PROFESSIONAL EXPERIENCE**

2013 – present Clinical Nurse Reviewer, Commonwealth Medicine-Disability and Community Services, Acquired Brain Injury Waiver Unit Shrewsbury, MA  
2012-2014 Adjunct Faculty, Salter College, West Boylston, MA  
2007-2013 11-7 Nursing supervisor, Holden Rehabilitation and Nursing Center, Holden, MA  
2006- 2007 Assistant Director of Nursing, Wingate at Brighton, Brighton, MA  
2005-2006 Clinical Documentation Coordinator, Wingate at Brighton, Brighton, MA  
2004-2006, Charge Nurse, Whittier Rehabilitation Hospital, Westborough, MA  
2004-2005, Staff Nurse (Per Diem), Beaumont Rehabilitation and Skilled Nursing Center, Westborough, MA  
2000-2004- Personal Care Attendant, Whitney Place Assisted Living, Westborough, MA

## **TEACHING ASSISTANT**

Sept 2014 – Jan 2014	N 210 Human Growth and Development: Throughout the Life Cycle
Feb 2015- May 2015	N 418 Nursing Care of Families
Sept 2015 – Jan.2016	N 701 Health Care Quality
Feb. 2016 - May 2016	N420 Introduction to Nursing Research
Sept. 2016- Jan. 2017	N315 Health and Physical Assessment in Nursing
Feb 2017 - May 2017	N420 Introduction to Nursing Research

## **RESEARCH PROJECTS**

Principal Investigator: “Return to Community”-The Process of Adults, 18-65 years with Traumatic Brain Injury, transitioning from long-term healthcare facilities to community  
Dissertation prospectus defended 2/13/17

Principal Investigator: Community Integration: The lived Experience of Traumatic Brain Injury (TBI) Survivors who transitioned back into the community after acute inpatient Rehabilitation, August 2015 – January 2018.

## **PUBLICATIONS**

Oduro, I., Ellis W.O., **Aryeetey, S.K.**, Ahenkora K., Otoo J.A. (2000) Pasting characteristics of Starch from new varieties of sweet potatoes. *Tropical Science*, 40(1), 25-28

## **MANUSCRIPTS IN PREPARATION**

Abbeyquaye, S.K., & Jacelon, C. (2018) Transitioning from a long-term care facility to the community under Medicaid Home and Community-Based Service Waiver Programs. An Integrative Review submitted for review 5/17/18

Abbeyquaye, S.K. (2018) Exploring Community Integration Among Individuals with TBI and their Family Caregivers.

## **SERVICE PROPOSAL & GRANTS**

Principal Investigator: “Return to community”-The Process of Adults, 18-65 years with Traumatic Brain Injury, transitioning from long-term healthcare facilities to community. Submitted to Graduate school UMass Amherst. Amount requested \$1000. Proposal request not funded

Principle Investigator: Return to Community- The process of transitioning from Long-Term Care Facilities to home of Young and Middle-Aged Adults with Traumatic Brain Injury. Submitted to Rehabilitation Nursing Foundation. Amount requested \$29,827. Proposal request not funded

## **ORAL PRESENTATIONS**

Abbeyquaye, S.K (2017) Transitioning to the Community; What Does It Entail? Association of Rehabilitation Nursing (ARN) 43<sup>rd</sup> Annual Conference, Seattle, WS.

Abbeyquaye, S. K. (2016) A Scalable Model for Successful Integration: Hot Tips for Where Support is Most Effective, Commonwealth Medicine, Cultural Diversity Committee, Lunch and Learn University of Massachusetts- Disability and Community Services Shrewsbury, MA

Abbeyquaye, S. K. (2015) Community Integration: A Concept for Nursing Practice, Association of Rehabilitation Nursing ARN, 41<sup>st</sup> Annual conference, New Orleans, LA

## **POSTER PRESENTATION**

Abbeyquaye, SK. (2018) Concept Clarification of Community Integration Among Individuals with TBI and their Family Caregivers, Eastern Nursing Research Society (ENRS), 30<sup>th</sup> Annual Conference, Newark, NJ

Abbeyquaye, S. K. (2015) Community Integration: A Concept for Nursing Practice, ARN, 41<sup>st</sup> Annual conference, New Orleans, LA

## **OTHER PRESENTATIONS**

Nov-2015 Guest speaker on immigrant health to third year nursing students at the University of Massachusetts Amherst, Amherst, MA

Oct 2015- Expert testimony to the State Senate Financial Services Committee on An Act Relative to Cognitive Rehabilitation S 485/H 843 on Behalf of the Brain Injury Association of Massachusetts, Massachusetts, Boston, MA

## **VOLUNTARY WORK**

Case Management Special Interest Group Leader at 43<sup>rd</sup> Annual Conference Association of Rehabilitation Nursing (ARN) November 2017, Seattle, WA.

Member of ARN Transition of Care Task Force- Working on a comprehensive systematic review of care transitions. October 2017 -Present

## **GLOBAL INITIATIVE**

President and founder of St Roses North America Inc- A 501c alumni foundation (Jan 2015-present). Foundation's mission is to provide funding to develop St Roses Senior Secondary School in Akwatia, Ghana and promote creativity and innovation of its students to be global female leaders. <http://strosesnorthamerica.org/>

## **REFERENCES**

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